

# Middlesex University Research Repository

An open access repository of

Middlesex University research

<http://eprints.mdx.ac.uk>

Kelly, Lorraine (2010) Using the patient experience to develop a model of care for breast cancer follow-up. PhD thesis, Middlesex University. [Thesis]

This version is available at: <https://eprints.mdx.ac.uk/6230/>

## Copyright:

Middlesex University Research Repository makes the University's research available electronically.

Copyright and moral rights to this work are retained by the author and/or other copyright owners unless otherwise stated. The work is supplied on the understanding that any use for commercial gain is strictly forbidden. A copy may be downloaded for personal, non-commercial, research or study without prior permission and without charge.

Works, including theses and research projects, may not be reproduced in any format or medium, or extensive quotations taken from them, or their content changed in any way, without first obtaining permission in writing from the copyright holder(s). They may not be sold or exploited commercially in any format or medium without the prior written permission of the copyright holder(s).

Full bibliographic details must be given when referring to, or quoting from full items including the author's name, the title of the work, publication details where relevant (place, publisher, date), pagination, and for theses or dissertations the awarding institution, the degree type awarded, and the date of the award.

If you believe that any material held in the repository infringes copyright law, please contact the Repository Team at Middlesex University via the following email address:

[eprints@mdx.ac.uk](mailto:eprints@mdx.ac.uk)

The item will be removed from the repository while any claim is being investigated.

See also repository copyright: re-use policy: <http://eprints.mdx.ac.uk/policies.html#copy>

**USING THE PATIENT EXPERIENCE TO DEVELOP A MODEL OF CARE FOR BREAST  
CANCER FOLLOW-UP.**

**LORRAINE KELLY  
9541891**

**PhD**

**8<sup>th</sup> JANUARY 2010**

## **ABSTRACT**

Improvements in early detection and treatment of breast cancer and the reduction in mortality rates have led to an expansion in the numbers of patients accessing breast cancer follow-up clinics (Montgomery and Dixon 2008). This has resulted in a need to review follow-up services to address the current situation to the best effect (Burnet, Chapman, Wishart and Purushotham 2004). To meet the aims of the Cancer Plan (Department of Health (DOH) 2000) and more recently the Cancer Reform Strategy (DOH 2007) as well as the needs of the patients a reconfiguration and development of existing services at the study site was required.

The primacy of the stakeholder's views was the driving force behind the research design. The research approach was used to involve the views of the patients, GPs, the clinical team and key people based in the NHS Trust. A focus group was used to identify the issues for patients and one-to-one interviews with GPs. These themes informed the patient and GP questionnaires. Key Informant interviews were conducted with members of the Multidisciplinary team (MDT) and key members of the clinical team.

The study outlines the nature of breast cancer follow-up services and the complexities associated with a diagnosis of cancer. This is from both the psychological and physical perspective and the impact it has on patients. Key themes emerge from the data about the breast cancer service as it is delivered at present and the expectations and perceived value of breast cancer follow-up. The involvement of the patients as key stakeholders ensured that their voices were heard alongside those of both hospital and primary care staff.

Themes from the questionnaires, focus group and key informant interviews concurred with each other. The need for reassurance that the cancer had been treated and participants

were well was very important in breast cancer follow-up. Another important element was the continuity of care and the relationship with the MDT (multidisciplinary team). A good relationship instilled confidence in the patient's management rather than continual questioning requiring the same clinical information from the patient. Following a diagnosis of cancer and a period of uncertainty, confidence in the team was paramount. The vulnerability of the women was discussed, due to the sexual nature of the breast examination and the fear of recurrence caused women a lot of anxiety. Moreover the importance of the examination to the women was discussed and the importance of consistency in examination technique. Therefore communication between the MDT and the patients about treatment, health education and the opportunity for the women to talk and ask questions helped to reduce anxiety.

All stakeholders discussed a model of shared care but aspects of patient management and resources would need to be in place to ensure safe practice. GPs did highlight some disadvantages to hospital based follow-up such as long waits, travel and lack of continuity. There was also dispute between hospital clinicians about clinical expertise and the transfer of care to community services. This was also raised by GPs and an element of developmental work would need to develop in a new model of care. The patients wanted to be seen at hospital but were not averse to being seen in the community setting.

To conclude the study findings concurred with the literature related to reassurance gained from attending follow-up clinics. However, NICE (2002) do not appear to take into account the views of the users and the importance of this element of multifaceted cancer care. As at the time of diagnosis of cancer there is time to make a decision, in follow-up there should be set junctures at which to discuss living and coping mechanisms. It may be at the end of cancer treatment some patients will require more follow-up than others. Follow-up may need to be individualised where some patients are discharged but others require

more support thus moving away from the exact same follow-up programme for all as happens now.

## **ACKNOWLEDGEMENTS**

It was the frustrations that I experienced in my work as a nurse and not least as the daughter of a breast cancer patient that prompted me to pursue this study in the hope that I could make a positive contribution towards the improvement of the system of breast cancer follow-up care in its different dimensions. The feasibility and fulfillment of such an undertaking depend, to a great extent, on the co-operation and encouragement of many people towards whom the researcher feels a deep debt of gratitude.

It is with a great respect and appreciation, therefore, that I acknowledge the help and guidance of my supervisors, Dr Kay Caldwell and Ms Lynne Henshaw. Their forthright frankness and constant attention and kind understanding kept me on track towards reaching rational conclusions. I gratefully acknowledge the courteous services afforded to me by the staffs of the R.C.N. Library and the Middlesex University Library. Their help and professionalism eased my efforts in research. I am also grateful to the Consultant Surgeons and Consultant Oncologists who so willingly discussed the subject of my study with me and encouraged me in my efforts. I am very grateful, too, to the many G.P.s and the members of the M.D.T. for the wisdom and insight which they gave me and for the patience and generosity which they showed towards me. I thank the Education Department of the Hospital Trust for making funding available to me to pursue this study and I am especially thankful to my nursing colleagues who so generously shared the extra case load so as to make this possible. I have a deep appreciation of the honest and sincere and heartfelt feelings and opinions of members of the Focus Group who discussed the subject of follow-up care with me. It was an outlet for them and an enlightenment for me.

Finally, I thank in a very special way my husband, my daughter and my son who have made so many sacrifices without complaint to facilitate me in bringing this project to its

conclusion. I also thank my extended family and friends who have patiently borne my preoccupation with this study. I am especially grateful to Mr Jim McAuley who has been a tower of strength for me throughout this study and a very dear uncle.

It is my hope that all the kindness and generosity shown towards me will be justified and rewarded by an outcome of the study which will find expression in the implementation of an enhanced system of follow-up care that will promote the physical and psychological wellbeing of breast cancer patients.

## CONTENTS

<b>Chapter One – Introduction</b>	
1.0 Introduction	9
1.1 Breast Cancer: The Context	10
1.2 International Comparisons	17
1.3 United Kingdom (UK) Cancer Policy	22
1.4 Resources For Cancer Services	30
1.5 Summary	35
<b>Chapter Two – Conceptual Framework</b>	
2.0 Introduction	39
2.1 User Led Research	40
2.2 Psychological Impact of Diagnosis and Treatment	41
2.3 Social Constructs	44
2.4 Summary	58
<b>Chapter Three – Literature Review</b>	
3.0 Introduction	60
3.1 Breast Cancer Survival	60
3.2 Breast Cancer Follow-Up	63
3.3 The Developing Role of Nurses	84
3.4 Peer Support	91
3.5 Government Policy in Supportive Care	94
3.6 Summary	97
<b>Chapter Four – Methodology and Methods</b>	
4.0 Introduction	101
4.1 The theoretical Framework to underpin the methodology	102
4.2 The Aim and Purpose of the Study.	103
4.3 The Research Questions	103
4.4 The Study Approach and Design	104
4.5 Ethical Considerations	110
4.6 Sampling	115
4.7 Data Collection	119
4.8 Data Analysis	125
4.9 Strategies to Ensure Rigour	129
4.10 Reflexivity	132
4.11 Summary	137
<b>Chapter Five – Interview Findings</b>	
5.0 Introduction	140
5.1 Results of Patient Focus Group and GP Key Informant Interviews	140
5.2 Results of Key Informant Interviews with the MDT	159
5.3 Summary	187



<b>Chapter Six – Survey Findings</b>	
6.0 The Patient Survey	189
6.1 Sample Demographics	189
6.2 Experience of Current Service	194
6.3 Views of The Current Service	197
6.4 The Benefits of Breast Cancer Follow-Up Clinics For The Patients	200
6.5 The Acceptability of Different Types of Breast Cancer Follow-Up Clinics	204
6.6 GP Sample Demographics	205
6.7 Views of The Current Breast Services	207
6.8 Views on Alternative Modes of Breast Cancer Follow-Up	208
6.9 Views on GP Involvement In Breast Cancer Follow-Up	210
6.10 Summary	210
<b>Chapter Seven – Discussion of Results</b>	
7.0 Introduction	213
7.1 Key Issues In Breast Cancer Follow-Up	213
7.2 Analyses of Mixed Methods	237
7.3 Alternative modes of Follow-up	239
7.4 Summary	248
<b>Chapter Eight – New Model of Breast Cancer Follow-Up Care</b>	
8.0 Introduction	252
Strengths and Weakness	
8.1 Developing a New Model of Care	253
8.2 Recommendation for Policy	258
8.3 An Agenda For Survivorship	259
8.4 New Model of Breast Cancer Follow-Up	261
8.5 Summary	266
<b>References</b>	270
<b>Appendices</b>	337
<b>Abbreviations, Synonyms and Nomenclatures</b>	356

## CHAPTER ONE

### 1.0 INTRODUCTION.

In the UK in 2006, 293,000 people were diagnosed with cancer and in 2007, 155,484 died of the disease ([www.cancerresearchuk.org/statistics](http://www.cancerresearchuk.org/statistics)). Currently one person in three living in the UK is liable to develop cancer during his/her lifetime. Over 70% of all cancers will occur in the 60 and over age group and, as our population gets older, clinicians will face an increasing number of patients at risk of, or presenting with, malignant disease Johnson and McDermott (cited in Spence and Johnson, 2001, p3). The survival rates for all cancers have risen steadily between 1986 -1999 ([www.cancerresearchuk.org/statistics](http://www.cancerresearchuk.org/statistics)). UK cancer incidence trends in the ten-year period 1997 to 2006 have remained fairly constant. There has been a slight decrease in men (by 1%) and a slight increase in women (by around 2%) ([www.cancerresearchuk.org/statistics](http://www.cancerresearchuk.org/statistics)).

Most people know someone who is living with - or who has died from - cancer. Some people have experienced the best treatment and care. Others have had distressing experiences. There does not seem to be a single cancer experience which applies to all people. This study investigates the management of follow up, once active treatment has been completed. One of the issues associated with breast cancer management involves gaining control of the early dissemination of the disease and the management of any recurrence. Post - operative and oncology follow-up has been initiated for patients with the main focus on early detection of recurrence at a stage where salvage treatment may still be curative. The debate is ongoing regarding what impact the accuracy of the diagnosis and early detection of metastatic disease has on overall survival. (Tomiak and Piccart 1993, Khatcheressian et al. 2006).

It has been extensively identified in the literature that, following cancer treatment many

patients are faced with a range of short term or long term problems such as depression, anxiety, fear of cancer recurrence, loneliness, and effects on family, environment and finances (Cox and Wilson 2003). At present, as stated previously, follow-up is concerned about the early diagnosis of recurrence and there does not appear to be a systematic tool to assist with these complex issues of survivorship. As cancer treatments improve people are living longer their management will require an inclusion of social, cultural and environmental assessment as well as their clinical assessments to ensure people are recovering from illness to wellness (Revenson and Pranikoff 2005).

In conjunction with the psychological and social adjustment to a cancer diagnosis breast cancer treatment varies from other cancer sites. Breast cancer now has extended adjuvant therapies which require monitoring and assessing for side-effects both physically and psychologically. These therapies such as Tamoxifen, Arimidex and Herceptin can be prescribed for many years and patients may use a combination of each drug. When discussing follow-up this is an important element to care and would need co-ordination between the various agencies over a long period of time.

In this introduction the aetiology of cancer and a brief background of cancer statistics will be discussed. Reflections on the international data and the impact of Government policy on cancer care will also be considered. The role of the multidisciplinary team (MDT) and its importance in the care of cancer patients will be highlighted including some of the complexities of involving users and developing patient-focused care.

## **1.1 BREAST CANCER: THE CONTEXT**

### **1.1.1. The aetiology of cancer.**

It is now accepted that cancer arises within a cell as a result of an accumulation of abnormalities or mutations of the DNA of that cell. When an abnormality occurs within key

genes, it can lead to uncontrolled cell growth - like taking one's foot off the brake. The key genes are those which are involved in control of the cell cycle or DNA repair. Russell (cited in Spence and Johnson, 2001, p17) explains this uncontrolled growth can eventually lead to the cell type having the ability to metastasise. Normal cell growth reproduces when instructed to do so by other cells. Such collaboration ensures that each tissue maintains a size and architecture appropriate to the body's needs.

Stem cell technology is a rapidly developing field. It combines the specialities of cell biologists, geneticists and clinicians and offers hope of effective treatment for a variety of malignant and non malignant diseases (Fontes and Thomson 1999). Stem cells are defined as totipotent progenitor cells capable of self-renewal and multilineage differentiation (Till and McMulloch 1961). Early research has focused on haematopoietic stem cells as solid tissue stem cells have not made the same progress due to the difficulty of reproducing the cellular interactions that exist in solid organs (Fontes et al. 1999). The ability for stem cells to integrate into the tissue makes them ideal for cell replacement therapy. In the late 1970s bone marrow and peripheral blood stem cell transplant started to be used for 'rescuing' patients using their own marrow after chemotherapy and radiotherapy. In the 1980s debate ensued regarding the evidence to support high dose chemotherapy and cell transplant due to the resulting toxicity (Kolata 1988). Data was sparse and authors always concluded that critical evaluation will require control trials (Antman and Gale 1988), (Cheson, Lacerna, Leyland-Jones, Sarosy, and Wittes 1989). In the U.S.A. many insurers would not cover cell transplant due to a lack of clinical data (Gilbert-Welch and Mogielnicki 2002). Researchers have found that adding stem cell transplantation does not improve survival but the length of time to recurrence was longer for women who underwent stem cell transplant (Hopkins Tanne 2003).

Cancer cells violate and become impervious to the usual controls on proliferation and

follow their own internal agenda for reproduction. They also have the ability to migrate from the site where they began, invading nearby tissue and forming masses at distant sites in the body (Weinberg 1996). There is a set of basic principles that govern the development of cancer it has been proven that the cells in a tumour descend from a common cell that at one point initiated a programme of inappropriate production. The malignant transformation of a cell comes about through the accumulation of mutations in specific classes of the genes within it. These genes provide the key to understanding the processes at the root of human cancer (Weinberg 1996). The cause of cancer is multifactorial and includes lifestyle, environmental factors and inherited genetic susceptibility. Johnston and McDermott (cited in Spence and Johnson, 2001, p.3) have documented that as many as 80-90% of all the cancers may be due to environmental or lifestyle factors.

Having discussed cancer in general, the focus of debate will now centre on breast cancer.

#### **1.1.2. Risk factors for breast cancer.**

In the absence of preventative measures for cancer, the control of cancer can in some instances be achieved through early detection and treatment. Opinions vary regarding the risks of developing breast cancer and strategies for its prevention and these will be discussed in turn. Several key risk factors have been identified that are related to the incidence of breast cancer:

- Genetic – Up to 10% of breast cancer in the Western world is due to a genetic predisposition (McPherson, Steel and Dixon 2000). The abnormal gene can be passed down through both sexes and can be transmitted but may not develop into breast cancer. It is not known how many abnormal genes there are but BRCA1 and BRCA2 are two mutations on chromosome 17 and 13 which account for a substantial

proportion of very high risk families to develop breast cancer (McPherson et al. 2000). A women's risk of breast cancer is two or more times greater if she has a first degree relative diagnosed premenopausal. The younger the age the greater the risk (McPherson et al. 2000).

- Age at first pregnancy - nulliparity and late age of first birth both increase the lifetime incidence of breast cancer. The risk of breast cancer in women who have their first child after the age of 30 is about twice that of women who have their first child before the age of 20. The highest risk group are those who have a first child after the age of 35. These women appear to be at an even higher risk than nulliparous (McPherson, et al 2000).
- Natural history of the disease - women with previous benign breast disease such as severe atypical hyperplasia have a four to five time's higher risk of developing breast cancer than women who do not have any proliferative changes in their breast. For women who have this change and a family history of breast cancer (first degree relative) the risk increases nine fold. Women with palpable cysts, complex fibroadenomas, duct papillomas, sclerosis adenosis, and moderate or florid epithelial hyperplasia have a slightly higher risk of breast cancer (1.5 - 3 times) than women without these changes, but this increase is not clinically important (McPherson et al. 2000).
- Life Style - there is a close correlation between the incidence of breast cancer and dietary fat intake, however; the precise nature of the relationship between fat intake and breast cancer does not appear to be strong or consistent. Obesity in postmenopausal women doubles the risk whereas among premenopausal women it is associated with reduced risk. Alcohol consumption has been linked in some studies but the relation is inconsistent but no relationship between smoking and breast cancer has been found (McPherson et al. 2000).

### 1.1.3 Prevention

Three large scale studies have investigated the potential for breast cancer prevention:

- The National Surgical Adjuvant Bowel and Breast Project (NSABP) is a clinical trials cooperative group supported by the National Cancer Institute (NCI). The NSABP was one of the first organizations to undertake large-scale phase III studies in the prevention of breast cancer and the Breast Cancer Prevention Trial (BCPT), which included more than 13,000 women at increased risk for breast cancer. It has been demonstrated that agents such as Tamoxifen either (1) inhibit estrogen action at the estrogen receptor (selective estrogen receptor modulators (SERMs); or (2) inhibit estrogen-synthesizing enzymes, thereby neutralising synthesis of this hormone (aromatase inhibitors). The National Surgical Adjuvant Breast and Bowel Project (NSABP) P-1: Breast Cancer Prevention Trial (BCPT) demonstrated the superiority of the SERM Tamoxifen to a placebo in reducing breast cancer risk. (Dunn, Wickerham and Ford 2005).
- The International Breast Cancer Intervention Study (IBIS-I), led by Professor Jack Cuzick (2001) from Cancer Research UK, undertook a study of the drug, involving around 7,000 women from the UK, Australia, New Zealand and Europe. The women were aged between 35 and 70 years and were at an increased risk of breast cancer. For example, they had a family history of the disease or had a benign lesion associated with an increased risk. The frequency of breast cancer was reduced by more than 30 per cent among women who were given the drug. This finding clearly establishes that breast cancer can be prevented, and clarifies conflicting results seen in previous studies. However, Tamoxifen has side effects such as increased risk of endometrial cancer and blood clotting. This was clearly explained to all the participants and the trial proceeded.
- The International Breast Cancer Intervention Study (IBIS-II) - This study has two arms and has been ongoing in the UK since 2004. The prevention arm investigates the role

of Anastrozole and whether it can prevent the disease in postmenopausal women at increased risk of breast cancer. This would include women who have a family history of the disease or that of ovarian cancer or associated benign disease. The second arm of the study, IBIS-II compares Tamoxifen and Anastrozole in the prevention of invasive breast cancer recurrence in women with Ductal Carcinoma In Situ (D.C.I.S.) (International Breast Cancer Study Group (IBCSG).

#### **1.1.4 Screening**

Sir Patrick Forrest developed the breast cancer screening service in 1988. It is a programme funded by government to screen all women from ages 47-73 every three years with double read mammography (National Health Service Breast Screening Programme (N.H.S.B.S.P) 2008). However, there is an ongoing debate about the effectiveness of breast screening with critics arguing that the presentation of information about the benefits of screening in terms of the relative reduction in the risk of dying from breast cancer is misleading (Gigerenzer and Edwards, 2003). Nyström et al. (1993) looked at a Swedish overview based on 282,777 women from 5-13 years in randomised controlled trials. This revealed a 24% (95 % confidence interval) significant reduction of breast cancer mortality for those invited compared with those not invited for breast screening. There was a consistent risk reduction associated with screening in all studies. In the Lancet, Danish investigators Gotzsche and Olsen (2000) published work which claimed that mammography did not save lives and actually could be harmful. The principal possible negative effect of screening could be over-diagnosis. There is a possibility that a woman might undergo unpleasant investigations and treatment without improving life expectancy or quality of life (Taylor 2005). Gotzsche et al. (2000) state that in the case of women aged 50-69, mammography reduces the chances of dying from breast cancer by about 35% although in the case of younger women there is only a slight benefit. The Danish researchers had criticised the scientific basis of many of the major trials used world-wide to



support national breast cancer screening programmes. However, the World Health Organisation (WHO) group, which re-examined the original studies, claims that the data provides sufficient evidence that mammography saves lives in older women (Kmietowicz, 2002).

#### **1.1.5 Treatment for Breast Cancer.**

Treatments for breast cancer include surgery and radiotherapy to control local disease and systemic treatment to combat frank or occult metastatic disease. Systemic therapies may also be administered as a primary treatment to reduce the size of the tumour prior to surgery (Cancer Research Campaign (CRC) 1997). Studies have shown that patients have a better prognosis if they are treated in specialised centres (Department of Health (DOH) 1995). As previously stated, breast cancer is a complex issue but it is an exciting time for breast cancer research. The cloning of breast cancer genes has been described as one of the scientific discoveries of the decade and investigations of high-risk families may help all women (CRC 1997).

With a rising number of women being diagnosed as having breast cancer, the socioeconomic burden of this disease is continually increasing (Tomiak et al. 1993). The Department of Health (1995) recommended a restructuring of cancer services so that high quality care might be delivered throughout the country. If successful this would improve national survival statistics without any advances in treatment (CRC 1997).

#### **1.1.6 Follow-up of Breast Cancer Patients.**

Follow-up examinations after potentially curative treatment of breast cancer have a number of functions. These include rehabilitation, evaluation of treatment and the detection of new primaries. However, the principle objective is the detection and treatment of recurrence (Tomin and Donegan 1987). Generally, patients are seen for follow-up every

three months for the first three years after diagnosis, every six months for the fourth and fifth years and yearly thereafter. There is international concern about the large number of patients that must be seen in breast clinics as breast cancer becomes a chronic disease. The situation will worsen, however, as breast cancers are detected at an earlier stage through screening programmes, a stage at which new therapeutic guidelines give promise of improvements in survival.

In critically reviewing breast cancer follow-up the literature review will examine matters arising around health and illness and how society views this and influences the choices that patients make. The link between the physical and psychological dimensions of these issues and how that link grows stronger as patients pass along that continuum will be debated. Furthermore, the diagnosis of cancer with the potential of pain, suffering and the risk of death bring a person and clinical expert into an existentially charged situation that requires careful management. These episodes of care require investigation as patients require a trust in their clinical team to survive their cancer and to have an expectation of their roles in the clinical relationship.

## **1.2 INTERNATIONAL COMPARISONS**

There have been many recent advances in the treatment of cancer. However, despite improvements, outcomes for cancer patients in the UK vary considerably and do not compare favourably with those in other European countries (Coleman et al., 2003). This analysis comes from the EUOROCARE Project which was set up in 1989 to measure and explain international differences in cancer survival in Europe. The aim of the project was not to establish league tables or develop national rivalries, but to estimate the range of survival rates and therefore identify regions and countries in which survival could be improved (Coleman et al 2003).

### **1.2.1 Cancer survival**

The first EUROCARE report identified substantial differences in survival for many cancer cases for the first time. It covered 800,000 cancer patients who were diagnosed during 1978-1985 and was followed up to the end of 1990 by 30 population based cancer registries in 12 European countries (Denmark, England, Estonia, Finland France Germany, Italy, The Netherlands, Poland Scotland, Spain and Switzerland). International differences for survival were not large for tumours amenable to cytotoxic therapy such as testicular cancer and Hodgkin's disease. For cancers where survival depended on early diagnosis and curative treatment by surgery and /or radiotherapy the survival rates were more widely spread across Europe (Coleman et al 2003).

The EUROCARE-2 study showed there had been improvement from 1994, except for Eastern Europe. EUROCARE-2 included 1.3 million cancer patients diagnosed with one of 42 cancers during 1985-1989 and follow-up to the end of 1994. Survival was the highest in Sweden, The Netherlands, France and Switzerland and was lowest in Poland, Estonia, Slovakia and Slovenia. Survival in England, Scotland and Denmark was often low in the case of tumours such as lung, breast, stomach, large bowel, prostate and kidney (Coleman et al 2003).

Recent data indicates that the survival from cancer is improving in the UK (United Kingdom) but when focused on local PCTs (Primary Care Trusts) there is regional variation in relation to possible late diagnosis which impacts on survival, an issues to discussed in the next section ( Mayor 2009). However, the issue of survivorship from cancer and the chronic nature of breast cancer and it long treatments indicates there maybe difficulties for patients. The central issue of cancer recurrence is a driving force for women to attend follow-up clinics (Okamura 2005). The side effects from long term hormonal manipulation and new treatments such as Herceptin require discussion and

monitoring (Revenson and Pranikoff 2005). McKinley (2000) eloquently writes about the loneliness when treatment at the hospital finish and the support needed to recover. These elements of care need to be investigated. The Cancer Plan (DOH 2000) and the Cancer Reform Strategy (DOH 2007) are diagnostically loaded to ensure cancer targets are met and patients are treated in a timely manner which links into amending the PCT variations of cancer mortality (Mayor 2009). Nevertheless, the survivorship needs of these patients still need to be met to enable them to recover from their cancer and the treatments.

### **1.2.2 Diagnostic delay**

The reasons underlying Britain's poor performance are not clear. The first problem could be the delay in diagnosis. Sikora (1999) argues that this seems unlikely to be a major factor as the stage distribution of cancers in Europe is broadly similar. The quality of primary care is high, he writes, with reasonable access to secondary diagnostic services, so delays in diagnosis are minimal. Summerton (1999), a clinical lecturer in primary care, disagrees with Sikora's argument. He highlights that The Medical Defence Union has reported that failure and delay in diagnosis consistently account for nearly one third of notified complaints concerning general practitioners. Interestingly as stated previously recent data concurs with Summerton, ten years on, that late diagnosis maybe key to regional variation in survival (Mayor 2009).

Sant, Berrino, and Coeberg (1999), an Italian epidemiologist, also discusses the delay in diagnosis and the consequent impact of this on the different stages of disease at presentation. Sikora (1999) stated that the stage distribution, whether advanced or not, was similar in all European countries, did not consider these factors significant. Evidence shows that survival in England was considerably lower than the European average for tumours treated mainly by surgery (tumours of the stomach, colorectal, kidney and breast). Since stage at diagnosis is more important for tumours treated by surgery than for tumours

treated with chemotherapy, these data suggest that advanced stage at diagnosis is a major reason for low cancer survival in England (Sant et al.1999), (Mayor 2009).

Analyses of the existing EUROCARE database show that differences in survival from breast cancer between countries were observed within the first six months after diagnosis. The excess risk of death within this period was higher for the United Kingdom than for European patients overall. After this period the difference in excess risk of death narrowed (Sant et al. 1998). This would suggest that advanced stage of diagnosis is a major determinant of low survival from breast cancer.

### **1.2.3 Cancer services**

The Eurocare Study (Sant et al. 1998) also highlighted a concern that some specialists seemed to do cancer surgery more effectively than generalists. However, apart from breast cancer surgery the data appeared conflicting. In order to investigate the difference in cancer treatments and survival benefits, cancer was viewed as part of the political agenda. UK mortality statistics for 2000 showed that the age of mortality from lung cancer in men had fallen from about 857 deaths per million population in 1991 to 608 deaths per million in 2000, continuing a downward trend since the 1970s (Mayor 2003).

EUROCARE-3 includes information on survival up to five years after diagnosis for 1.8 million adults and 24,000 children who were diagnosed with cancer during 1990-1994 and follow-up to the end of 1999. The countries participating include both some of the poorest in Europe and some of the most economically developed. Health systems in these countries vary widely. In Poland \$420 was the total expenditure per patient on health in comparison to Switzerland who spent \$2,555 per patient. Therefore international data will vary (Coleman et al. 2003).

EUROCARE 4 and 5 includes additional countries and patients diagnosed between 1995 and 2002. Survival and surveillance data is compared with data from EUROCARE-1,-2 and -3 ([www.eurocare.it](http://www.eurocare.it)).

#### **1.2.4 Improvements in survival**

Survival of UK patients after cancer is improving but still lags behind the European average despite the UK spending more than other countries (O'Dowd 2007). Analysis for patients diagnosed during 12 years from 1983 to 1994 and followed up until 1999 has been documented. Survival for breast cancer has improved steadily in all European countries but at different rates. There has been some evidence of a more rapid improvement in survival in the UK which may be due to mammographic screening (Robinson, Bell and Møller 2000) and treatments (Quinn and Allen 1995). However, while improving, the figures appear to be below the European average and to be the same as those of other nations who spend less than the UK on cancer. Nevertheless, experts on cancer have defended the new data, explaining that it was captured prior to the implementation of strategies to improve cancer services, such as, the Cancer Plan (2000) and that the data is complicated and should not be over simplified causing huge anxiety to patients (Yates 2007).

The improvement in survival and treatment reinforces the need for surveillance in a coherent way using a population-based cancer system which is able to monitor variation of incidence and survival of cancer over time <http://www.statistics.gov.uk/> (Office for National Statistics). Nevertheless, the cancer registries differ considerably in their methods of data collection. Some employ clerks to collect data, others use hospital record staff and several rely on the Trusts' computer systems. Therefore data can be collected by different people in different places, weakening consistency. In addition, reporting of cases is also different and ascertainment of the data can be achieved by comparing the number of registrations

and deaths in a period. However, this has limitations as there is variation across regions (Office for National Statistics 1999). An audit comparing the quality of data in cancer registration within the UK was published in 1995. Variations among registries were found in data quality for diagnostic factors, incidence, and stage of disease, treatment and use of death information. The review found that the quality of the data depended heavily on the competence and experience of the staff in the registry and on maintaining good relationships with clinicians and staff including scientists in the active involvement of research.

### **1.3 UNITED KINGDOM (UK) CANCER POLICY.**

#### **1.3.1 The policy framework**

Since 1997 cancer is viewed by Government as a top priority and new resources have been allocated to its treatment and care. There has been the development of the Cancer Action Team, a National Cancer Director and a National Cancer Plan (DOH 2000), proposing national standards and a vision for cancer services in the future (DOH 2007).

In 1995 The Calman-Hine Report discussed the principles of a good service. Dame Deirdre Hine and Sir Kenneth Calman took an important step in providing a vision for cancer services. They indicated that there was a need for parity of service and for issues around access for patients to high quality local health services (DOH 1995).

In 1996 The Clinical Outcome Guidelines for Breast Cancer were published (DOH 1996). These guidelines set standards for clinical practice and ensure parity across the country. Unfortunately, the guidelines did not establish any central plan for implementing its proposals. Individual regions were expected to implement the guidelines in response to local need. Moreover, no additional resources were provided at the time for these tasks (Sikora 1999). Each region developed its own strategy. Some developed cancer units and cancer centres with systems put in place to monitor their practice. However, some

regions were more vigorous than others. This varied approach meant a lack of parity in cancer service delivery across the country (Commission for Health Improvement and the Audit Commission) (CHI/AC 2001).

The Cancer Plan in 2000 set out the first comprehensive strategy encompassing prevention, screening, research, treatment and palliative care. It discussed the investment needed to deliver these services in terms of staff, equipment, drugs and information (DOH, 2000). Prior to the publication of the National Cancer Plan, The Commission for Health Improvement and the Audit Commission (CHI/AC) jointly participated in a national review of cancer services of which the author was one of the field workers. The review was to document the experiences of people with cancer and the complexities of the multiple services with which they come into contact (CHI/AC 2001). The review was concerned to learn how the quality of services might be improved and how resources might be used to best advantage. The improvements found in one region raised the question as to why these strategies could not be implemented elsewhere.

The Cancer Service Collaborative “Improvement Partnership” (CSC-‘IP’) have developed and redefined patients’ cancer pathways. New approaches to care are being adopted to make a real difference to the patient experience. One of these “High Impact Changes” is to address cancer waiting times. All Strategic Health Authorities (SHA) have local delivery plan agreements with the Department of Health which include delivery of the 31 and 62 day target on a commissioner basis. This target requires that all patients should not have to wait more than one month from diagnosis to first treatment and the second target requires that 62 days be the maximum waiting period from urgent GP referral to first treatment. As part of the local performance management arrangements SHAs and Primary Care Trusts (PCT) will be working with local health partners to plan, support and manage delivery of the cancer wait times targets and the Cancer High Impact Changes



are a key to this (CSC-IP 2006). At present these targets are at diagnostic and first treatment stages alone.

### **1.3.2 Developing patient and public involvement**

The Government supports the notion that involving patients has contributed to change in the provision of services across a range of different settings. One of the factors which has put a focus on user involvement has been the introduction of a competitive market which requires prioritisation of services and a move from the paternal style of medicine. (Small and Rhodes 2000). Documents such as the Patient's Charter (D.O.H. 1991), 'Your Health, Your Care Your Say' DOH (2005a), 'A Stronger Local Voice: A Framework for creating a stronger local voice in the development of health and social services'. (DOH 2006) urged managers to consult with their local populations. Local Voices provided guidance to commissioners to take account of people's views but those responsible for its implementation were not accountable to the public (Small et al. 2000). There is often debate around differing levels of 'need'. With finite resources for the NHS there should be systems in place to meet the needs of all the stakeholders. Spek (cited in Hauser 1972) developed a classification of need:- needs of society, needs of experts and the individual's needs. However, Bradshaw (cited in Popay and Williams 1994, p46) describes need as a modern concept and explains that historians have been preoccupied with minimum existence and poverty. Bradshaw (cited in Popay and Williams 1994, p46) argues that need is too inaccurate and it may be more appropriate to consider inequality and the complexities associated with social, educational and financial need and how they impact on health.

To facilitate expansion of user involvement there were five modernisation action teams set up to achieve sustainable change:

- Partnership - Health and social services to work together.

- Prevention - To work with issues in the promotion of health.
- Professional – To ensure that services are patient centred and that the staff have the right skills to achieve high standard of patient care.
- Performance - To involve the users in the shaping of services.
- Patient access - To ensure that services are convenient and attainable in a fast and safe manner.

The Modernisation Agency led the drive to ensure an effective, accessible service. Documents such as the Cancer Plan (DOH 2000) will help steer these initiatives. The Cancer Plan (DOH 2000), The National Service Framework (CHI/AC2001) and the Cancer Reform Strategy (DOH 2007) are shifting the balance of power away from the clinicians. The Health Care Act of 2001 makes managers accountable with the development of overview and scrutiny committees (OSCs) charged with identifying any gaps in patient care. These views are contested with or without the Secretary of State. There is a duty on all NHS bodies to involve patients. The Secretary of State has created Independent Complaints Advocacy Services to help develop this strategy. In addition to this, Patient and Public Involvement Forums (PPI Forums) exist in all NHS trusts (including foundation trusts) and PCTs to improve the quality of NHS services by bringing to trusts and PCTs the views and experiences of patients, their carers and families. The forums are being presented as a crucial element of the drive to boost the public's involvement in decision-making about health and the local services they receive. The volunteer members will have 'unprecedented powers' to go where the patient goes, independently scrutinizing the quality of local health care, finding out what people really think and taking action where necessary. For example, they can demand a response from the NHS, within a strict timescale, to any comments or recommendations. The hope is that together, the forums will play a vital role in influencing local and national decisions, acting as a force for fairness and change (O'Hagan, Carroll and Dodds 2005).

The Patient and Public Involvement (PPI) Forums have leads in each organization to ensure patient and public involvement is embedded throughout the patient experience using a framework in collaboration with other lead clinicians and staff. There are frameworks which require assessment; these assessments are in line with existing targets in the NHS and are linked with the five key dimensions for achieving a good patient experience. Dealey (2005) describes the role of the Primary Care Trusts (PCTs) as no longer directing patients to specific hospitals for treatments but in future to offer patients the opportunity to choose from four or five local hospitals and all the foundation trusts and nationally procured independent sector treatment centres. This will have an effect on 'payment by results'. The policy 'payment by results' is intended to provide incentives to increase efficiency and improve access by introducing a number of tariffs for different patient groups such as long and short stay patients (DOH 2003). Ultimately there will be a national tariff which will make it easier for patients to select alternatives to their local hospital. Thus trusts need to develop a strategy to address the issues that provide secondary and tertiary care.

Entwhistle, Renfrew, Yearley, Forrester and Lamont (1998) suggest a hierarchy of terms ranging from involvement to consultation and participation. User Involvement is not about user control but about providers listening to users so that their views may influence the provision of services (Andrews, Manthorpe and Watson 2004). The 'ladder' of user participation developed by Arnstein (1969) has proved of enduring value in setting out the possible interpretation of user involvement. However, the criticism has been made that the ladder does not accommodate the complexities and range of user involvement (Small et al. 2000). The term user, consumer, client or customer depends on the role in which they are involved. These terms distinguish between a commercial/economic approach in which consumers exert power through the choices they make. Hirschman (1970) describes 'exit'

as consumers transferring their business elsewhere and 'voice' as seeking a change in service.

*"Whereas 'exit' is broadly compatible with a market approach, 'voice' accords with more a democratic approach whereby service users, or the wider public might seek to influence the overall pattern of service."*

Small et al. (2000) p 20.

### **1.3.3 The benefits of user involvement.**

In the field of cancer care a number of support groups have developed. Cancer support groups can potentially reduce distress by providing information about cancer and its treatment, offering emotional support, and teaching coping strategies and function on the basis of mutual aid. They meet regularly for discussion with peers and this involves listening, reassurance, comfort, and caring. There are certain things about living with cancer that those not suffering from cancer will never understand. (Miyashita 2005). Several studies suggest that support group intervention can improve some of the psychosocial problems that arise following cancer (Montazeri et. al. 2001).

Support groups and a network of local support may help promote self empowerment in the psychosocial aspects of cancer (Speigel, Bloom and Yalom 1981). Alternatively support groups can offer services not provided locally. Cancer support groups can also influence service planning and development by providing a perspective grounded in their own experience of the disease. In the long term this can increase open communication between patients and professionals and can therefore bring about positive changes to assist with service development. Richards (1998) states that greater user-involvement in health care will be in everyone's best interests.

Medicine has traditionally assumed the power to decide what treatment individuals should

receive and therefore a change in the balance of power in favour of patients means decisions may be made regarding care in an holistic manner. Canter (2001) explains that the balance of power is more complex and that practices such as coercion, charisma, rewards for actions, legislation and knowledge base, play a part in the exercising of power. Medicine is generally the domain in which healthcare staff have more knowledge. However, patients can have greater knowledge of the varied symptoms and effects that disease process and treatments have on their health and individual lives. Especially in the case of chronic or rare illnesses, patients could be better informed than many healthcare staff (Kennedy 2003).

#### **1.3.4 Challenges of user involvement.**

Gray, Fitch, Davis and Phillips (1997) reports increased stress levels among users when learning about the problems that exist and the difficulties in finding effective solutions. The peer review process assesses cancer management in local areas by other clinicians from different cancer networks. Users are encouraged to be involved in this process but there does not appear to be structured support for the reviewers to discuss the process and outcomes. Within Gray et al. (1997) it emerges that feelings of dissatisfaction, tokenism and the perceived disinterest of clinicians did not encourage users to participate. Furthermore, practical issues regarding timings of meetings were organised around the convenience of the professionals rather than the users. However, Richards (1998) states that patients should know more about the variance in practice. She stated that a more open and equitable exchange is also likely to increase patient satisfaction and perhaps more likely to encourage patients to participate in randomised controlled trials.

Another criticism of user involvement groups is that they may not represent the population as a whole. Gray et al. (1997) highlights the importance of adequate input from ethnic and differing socioeconomic groups and also the importance of a constant flow of new

volunteers. For some the symptoms, disease and treatments may inhibit them from involvement (Robson, Locke and Dawson 1997). Clinicians have also expressed concerns regarding user involvement. These include the negative effects of exposing patients to clinical uncertainties. However, others report that an awareness of these uncertainties is beneficial as it highlights a scientific bias of medical interventions (Richards 1998).

The implementation of PPI raises many questions. How, for example, can we make services personal, given that the NHS sees a million patients every 36 hours? (Fenton 2005) The new Foundation Trusts are to have greater freedom for top-performing NHS hospital trusts. As Fenton (2005) states in her article patient choice and the roll out of foundation trusts will be increasingly important.

*“After all, if we don’t listen to our patients now, we soon won’t have any to listen to”.*

Fenton (2005) p 3.

While it is true that trusts have been required to undertake baseline assessments of activity and to develop strategies for PPI, these requirements are rarely high on their performance agendas. After all, trusts would not ‘lose stars’ without them.

Hehir (2005) has concerns that becoming more responsive to patient needs will further undermine public trust and confidence in the health service. Major enquiries such as The Bristol Royal Infirmary Inquiry (2001), The Royal Liverpool Children’s Inquiry (2001), and Shipman – The Final Report (2005) have left a climate of mistrust and have put healthcare professionals under continual scrutiny (Watts 2003). The loss of trust has been compounded by the loss of self-regulation. This has been highlighted by the GMC in the

Shipman inquiry (Watts 2003). The public are now invited to be involved in aspects of professional life, education and peer review. Health care professionals feel squeezed both by government and the public. This has resulted in a further loss of confidence and professional autonomy. Hehir (2005) goes on to highlight that PPIs have been considered a 'good thing' within this evidence-based era, even though PPIs are not evidence based. PPIs are self-appointed and do not represent the public. They promote individualism and choice but choice is really elusive. The NHS is in a state of constant restructuring as it seeks to control services that secure the greatest value for money (Bradshaw 2001). Public expectations of what the NHS can deliver have also increased, but the investment needed to match these expectations has not. This often leaves staff feeling they provide less patient centered care.

#### **1.4 RESOURCES FOR CANCER SERVICES.**

##### **1.4.1 The cancer services infrastructure**

In line with the first principle of the Calman-Hine report (DOH 1995), the fundamental aim of Cancer Networks is to ensure that all patients served by the Network have access to a uniformly high quality of care in the community or hospital wherever they may live. It also aims to ensure the maximum possible cure rates and best quality of life. The Network aims to provide this care as close to the patient's home as is compatible with high quality and safe and cost effective treatment. Patients will be genuine partners in their care and treatment. Care will be provided in a fully collaborative multi-disciplinary, multi-professional and multi-agency setting in which all professional and administrative boundaries are invisible to the patient (Local Cancer Network Strategic Review 2003). At present the Cancer Networks do not have a financial budget but feeds into the negotiating bids for funding.

Difficulties arise from the competing targets of hospital Trusts. Locally a substantial proportion of the new cancer monies were not spent on developing cancer services. Of the monies available to the Network in 2001/2 and 2002/3, initial indications show that the actual profile of expenditure on NHS cancer plan developments (including NICE drugs) was half of the total earmarked. There appears to be a deficit within one Trust and cancer monies have been used to address this shortfall. It is difficult for PCT commissioners to support Network-wide developments while one part of the Network is consuming substantial new resources locally. Most of all, it fails to acknowledge the intention that current cancer money is for “new development”, not to prop up budgetary deficits. It fails to address the issue of network-wide decision making and it fails to present the concept of a functioning Network as opposed to funding one local area. (Strategy of one Cancer Network Strategic Review 2003). The House of Commons Committee of Public Accounts reported a review of all cancer networks, major variations in mortality and access to drugs in different parts of England and Wales. The Committee, as part of its role to examine public spending, found 30% of cancer networks assessed did not have comprehensive plans for providing cancer services or monitoring of services against the cancer standards. The Committee recommends that Strategic Health Authorities should review the effectiveness of cancer networks and put cancer plans in place where necessary (Mayor 2006). As the cancer networks do not have a budget and feed into the trusts business plan other deemed more urgent issues gain the finances such as drugs, personnel or medical devices. The re designing of follow-up to ensure the use of assessment tools for all the team to use to review how people are coping in following cancer treatment appears not a priority. This will be discussed further in the chapter in relation to policy and the reality of what occurs in the clinical area.

#### **1.4.2 The role of the multidisciplinary team (MDT)**

The Cancer Plan (2000) led to the development multidisciplinary teams (MDTs) working



across England and Wales. The MDT comprises core professionals: a specialist nurse, a consultant surgeon, a consultant radiologist, a consultant pathologist and a consultant oncologist. Each member of the team has a key role in coordinating the patient's pathway through diagnosis and first treatments (CHI/AC 2000).

Along with other important aspects of cancer care there is a need for health professionals to recognize the emotional distress of a cancer diagnosis, treatment and survivorship (Bultz and Carlson 2005). A new document such as the Supportive and Palliative Care (NICE 2004) document begins to standardise support offered to patients. Consequently nurses will be required to provide the additional skills of enablement to this client group and this will necessitate resources and training to facilitate this activity of care. The development of supportive roles in breast cancer care to meet the needs of the users will require education and practice which will need to encompass the complexities of the interventions required and the importance of maintaining a professional role within a supportive and psychological framework.

In line with opinion polls discussed by Small et al. (2000), the first cancer patient survey was undertaken 1999/2000. All NHS Trusts participated, identifying 65,000 patients who responded to the questionnaire. In 2004 The National Audit office commissioned Picker to undertake a similar, but smaller scale, survey to assess whether patients' experience of care had changed. Forty three thousand responses were received. Patients surveyed reported better experiences. Arguably the most important single change that has occurred in cancer service delivery over the past decade is the development of MDTs. The sequential development of cancer teams, including clinical nurse specialists, is likely to account for the differential improvements observed in the cancer patients' surveys between 2000 and 2004. This suggests that MDT working and the creation of CNS posts has had a marked impact on patient experience (Department of Health 2005b). However,

as Willard and Luker (2005) state from their study, supportive care is clearly important to those suffering from and affected by cancer. However, there appears to be a mismatch between current policy and reality – the reality that emphasises treatment at the expense of supportive care. If the dual demand of current cancer policy is to be met, then the MDT will need to be better resourced and will require better organisational support and guidance on monitoring achievements.

### **1.4.3 The characteristics of an effective MDT**

In the professional relationship between patients and their MDT there are qualities which patients deem to be necessary. Burkitt-Wright, Holcombe and Salmon (2004) found that patients wished to be treated by an expert. However, the need for other attributes as well as being an expert became apparent. The breast cancer patients in the study wanted to have trust in the team caring for them and for the team to have a personality. The consultant should have good eye contact and share conversations on unrelated topics, or perhaps be seen to do something he/she did not have to do. The patients wanted to be treated with respect and not to feel they were an inconvenience (Burkitt-Wright et al. 2004). These important qualities are inherent caring aspects of the MDT. Caring carries a multidimensional set of meanings. When considering a definition of caring, Mayeroff (1972) 'states that 'caring' for an idea is different from 'caring' for a person. However, there are similarities in that caring enables the idea or person to grow but that may depend on the commitment of the person who cares towards the other person or idea. In breast cancer follow-up where patients are recovering from an illness, which is synonymous with death, pain, and suffering, emotional distress is demonstrated across the trajectory of the illness. Consequently caring is an imperative part of the treatment (Bultz et al. 2005). Caring is to be found also in the intellectual and emotional temperament of the person who cares. Those dispositions would involve the facility and use of knowledge in moral values (e.g. honesty) and personal traits such as patience and humility (Mayeroff 1972). Mayeroff

(1972) includes the idea of caring as a task within his overarching ideas of commitment and humanitarianism. Ungerson (1987) suggests that the issues of commitment should be separated from performance of given tasks.

The interconnection between power and caring in the work of health provision has not been adequately explored. The extent to which professional caring might emerge from and be sustained within power relationships requires investigation (Hugman 1991). The delivery of health care is often a social activity due to the relationships which have been developed over time. This is particularly significant in cancer follow-up. An understanding of social processes is paramount in developing services and a framework to support it. Social change takes place due to attitudes and behaviour influenced by various factors: age, marriage, type of illness and the changes in illness and treatments. Likewise patients' expectations and the organisation and structure of the professions influence social change and health behaviours. The choices in seeking to improve breast cancer follow-up may be influenced by the close relationships within the MDT, by the different roles of its members and by the expectations of patients influenced by sociological factors.

This definition of care and the decisions as to who performs the caring, as well as where it takes place, is fundamental in developing a framework to meet the needs of all the users in breast cancer follow-up. These are interesting challenges and fundamental in supporting patients. The diagnosis of breast cancer as a life threatening illness causes anxiety and fear. Therefore care needs to incorporate a psychological aspect to the treatment and rehabilitation of the breast cancer patient. Walker and Eremin (1995) indicate that psychological factors may play a part in the aetiology and progression of malignant disease. Therefore, given the high prevalence of psychosocial and emotional distress, the essence of caring both physically and psychologically in a structured framework will foster a key element in developing a theoretical framework. Such a

framework is needed to underpin changes in both the clinical construction of follow-up as well as the social organisation of patient care. Salander (2002) analysed written narratives of newly diagnosed cancer patients. The narratives indicated that patients did not focus on communication skills but on various attributes. This emphasizes the need for a caring professional. Jefford and Tattersall (2002) discuss the dilemma of cancer patients requiring endless information. However, as Leydon et al (2000) highlight the reason that such an amount of information is needed is to provide some control, trust and hope for patients who have been diagnosed with a life threatening illness.

## **1.5 SUMMARY**

There has been much improvement in the treatment of cancer patients in the UK. The latest figures quoted indicate that the situation is not the disheartening disaster that is portrayed in EURO CARE-2 (Coleman et al 2003). The survival rate of people with solid tumours that are detected early has increased dramatically with improved surgery and chemotherapy (Mayor 2003). Clinically, progress is being made in cancer. With greater multidisciplinary collaboration and the application of research to influence practice, there should be an impact on patient outcomes.

There are strategies in place regarding cancer prevention. In relation to breast cancer there is a national screening programme in which debate is ongoing concerning the benefit of mammography and also the information people are given regarding the benefits and the possible harmful consequences of investigations. Furthermore, in light of technical advances in treatments the difficult issues are being addressed around treatments for new conditions, such as the diagnosis of non invasive cancer and its management (Taylor 2005).

The Government has been a driving force in reorganising and improving cancer services to guarantee that patients will be seen in a timelier manner. At present these initiatives appear to be at the beginning of the patient pathway. Developments in follow-up and psychological care need to be addressed. The important components, which the stakeholders value, need to be developed in a new model to ensure people have the ability to live through the cancer experience with appropriate professional support. Monies are also required to fund these important service delivery changes. Cancer networks need to be able to control finances in such a way that one deficit is not allowed to halt all other service development.

The work of the MDT has assisted in coordinating care and developing a team approach. Relationships between professionals and patients become durable and immutable as people survive the illness and treatments. To enable clinical development and critical thinking, sociological knowledge in healthcare is fundamental. It highlights the social causes of disease, exposes power-factors and ethical dilemmas thus creating focused and competent decision making in changing clinical practice (Morrall 2001). The practice of breast cancer follow up is laced with these complexities due to the nature of a cancer diagnosis, the expectation and the health beliefs of the users and the professionals involved and the close relationships between the patient and the members of the MDT. It appears that patients want to be treated by experts but there are other extremely important qualities of the MDT which are just as important as the chemotherapy or surgery (Burkitt – Wright et al. 2004). These issues of caring require commitment on the part of the MDT. There are roles within society expected of doctors, nurses and other medical professionals. If follow-up in breast cancer is to change, these social processes will need to be evaluated. In cancer follow-up social relationships develop over time between MDT members and their patients. Therefore these interactions will influence service delivery and what is acceptable to users.

Defining what is acceptable involves clarifying 'needs and wants'. At present service is designed for the greatest number. Individual need is not catered for within this model of care. Rawls (1972) describes an approach where the less well off are protected, where everyone has the right to dignity, confidence and autonomy. Within the diagnosis of breast cancer these key elements of caring are fundamental. Rawls' (1972) approach sees the needs of others as paramount as if the service were needed for oneself. The drive from government to involve users will aid this and it encourages responsibility for policy development and consideration of others with individual needs.

To fund the above developments is obviously a complex task. Cancer networks have been developed but do not have a financial budget and therefore do not have power to develop all services. Government objectives for all areas of health care cause conflict between cancer and other competing targets. At present targets are at the diagnostic and first treatment stages. Follow-up appears to be the Cinderella of the system. However, it is an important part of care as cancer has the potential of threatening all of a person's resources. It is as if the experience of cancer takes on a life cycle of its own that starts with the shock of diagnosis and continues well beyond the completion of treatment. As well as the awareness of roles in the MDT and ensuring all individual needs are met by involving all users, psychological support is required. Psychological interventions have been shown to have a major beneficial effect on helping patients adjust to the diagnosis and treatment of cancer (Meyer and Mark 1995). Participation in these services affords patients the opportunity to learn positive coping skills, to recognise that they are not alone, to discover how to enjoy living in the present, and to attach a different meaning to the words 'hope' and 'healing'. In follow-up as part of an ongoing treatment, psychological care can restore a sense of wholeness to one's mind, body and spirit. This is as important as receiving the most effective chemotherapy (Johnson 2000).

An organised approach to follow-up is crucial for the team that cares for the patient. An understanding of the sociological boundaries and conflicting power roles will assist the development of a follow-up service which will meet the clinical needs and the psychological and social needs of people with cancer as they move into survivorship. The distribution of power between the caring professions and the patient is a complex process. To hand over power from one to the other does not seem to be an easy measure. Issues, arising from government policy and economic restraints on services, influence patient decision-making. Patient power cannot be changed unless practice is changed. Freedom to choose services and choose doctors; freedom to seek further opinions and choose alternative treatments and practices; and the involvement of users in change will begin to highlight the uncomfortable fact that healthcare professionals do not hold a privileged position, controlling the power of patients to make their decision. When patients are diagnosed with a life threatening disease such as breast cancer both patient and loved ones are crippled with fear. How they deal with that fear will depend on their psychological make-up and past experiences. Patients need to be valued and acknowledged as individuals; they need to be encouraged to tell their story; they need to be given full and frank answers to all the questions they ask and only the questions they ask (Earnshaw and Reilly 2001). This study developed from a desire to improve the experience of patients who were facing their personal journeys through cancer, and centralise their needs in the structure and process of service delivery.

## **CHAPTER TWO**

### **CONCEPTUAL FRAMEWORK.**

#### **2.0 INTRODUCTION**

Defining the nature and model of care is fundamental in developing an infrastructure that is set up for breast cancer follow-up services. Challenges that are faced in supporting patients through the journey of a life threatening illness are complex and multi-faceted. The care that breast cancer patients require during treatment, rehabilitation and survivorship, encompass physiological, psychological and social components.

Discussions regarding the treatment and follow-up of breast cancer necessitate an insight into the nature of medical care, health and illness in order to underpin a strategic framework to guide change. A diagnosis of breast cancer encompasses the following operative concepts:

- Psychological impact of diagnosis and treatments.
- The sociological concepts, underpinning key relationships within the health care setting.
- The nature of user involvement and participation in the Health Service.

These concepts are part of what is a complex bio-psychosocial patient experience, and they underpin the way in which they are utilised to shape and structure the model of service delivery. In shaping a new model of breast cancer follow-up care it is vital to recognise the ongoing nature of therapies and support required. Many policy documents – The Cancer Plan (D.O.H. 2000) discuss the availability of treatment and diagnostic part of the patient journey. It does not explain the length of these treatments for a patient when they are prescribed and the support that will be required to ensure they are adhered to correctly. The ongoing nature of treatment, the side effects of these treatments and psychological impact are not discussed in policy or there are no plans in place to structure



a service to deliver follow-up care in this part of the patient journey.

## **2.1 USER LED RESEARCH**

The conceptual framework, which it is proposed to structure the breast cancer follow-up service, is based on a combination of Mishel's Uncertainty in Illness Model (Mishel 1988), the Stress and Coping Theory by Lazarus and Folkman (1984) and Ferrell's Quality of Life Model (Ferrell 1996). The strands from these models have been developed to illustrate how different aspects of our lives, such as social, situational interpersonal and temporal, can influence decision making and the relationship between personality and disease and influence coping with the diagnosis of breast cancer. These themes underpin one conceptual framework to provide holistic follow-up care both medically and psychologically for this group of patients. .

Mishel (1988) describes uncertainty in illness as that which is felt by the person who is unable to understand the meaning of an event because of its complexity and dichotomy between the patient's own expectations. In addition, this uncertainty affects how different strategies are used in helping people to cope in different situations.

Lazarus et al. (1984) define the adjustment to normal living as the reconciliation of physical illness, morale or life satisfaction with the ability to function at work and at home. Ferrell's (1996) model agreed with those of Mishel (1988) and Lazarus et al. (1984) but it included a physical, psychological, social and spiritual domain in its framework. To develop a model of care, these different domains need to be discussed in combination with the research findings and to be applied in the context of breast cancer follow-up. (Revenson et al 2005).

## **2.2 PSYCHOLOGICAL IMPACT OF DIAGNOSIS AND TREATMENT**

### **2.2.1 Experiencing distress**

There is ample documentation to support the assertion that receiving a diagnosis of cancer brings with it psychological distress, an emotional burden, a threat to survival and an impairment of self image (Taylor, Ismail, Hills and Ainsworth 2004, Zabora, Brintzenhofesoc, Curbow, Hooker and Piantadosi 2001). In this context distress has been defined as a “multifactorial, unpleasant emotional experience of a psychological, social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (Jacobsen 2005). Feelings of distress range along a continuum from sadness and vulnerability to disabling depression (Vachon 2006). Several studies have found that one third of cancer patients experience distress (Zabora et al. 2001) and nurses with a professional cancer background may experience a particular form of distress, when working as a member of the multidisciplinary team. This indicates that distress is not confined to the patient. This is termed ‘insider vulnerability’ due to the nurse’s extensive knowledge of the illness and her empathy with the patient’s distress (De Marco, Piccart and Agretelis 2004).

As people live longer after a diagnosis of and treatment for cancer, attention has turned to the quality of life and the distress patients have experienced by their illness. It has been recommended in the United States that all cancer patients are routinely screened for psychosocial distress as part of routine cancer care, including follow-up (National Comprehensive Cancer Network 2003). Lovejoy, Tabor, Matteis and Lillis (2000) discuss normal sadness associated with adjusting to a cancer diagnosis. However, if the sadness persists beyond two weeks, health care professionals should suspect depression and treat it aggressively, especially if core symptoms of depression are present. These include helplessness, hopelessness, poor self esteem, feelings of guilt or worthlessness and thoughts of suicide. During treatments many depression like symptoms are related to side

effects of therapies but can be manifestations of depression and, if left untreated, have been associated with decreased cancer survivorship (Vachon 2006). Amir and Ramati (2002) found that 18% of women treated for breast cancer in their study had full Post-Traumatic-Stress-Disorder (PTSD) and 58% had partial PTSD. The study found that women who were the least ill when receiving chemotherapy were most at risk for PTSD symptoms when examined 60 months after treatment. Once treatment has been completed, interventions may involve additional education by a member of the health care team or support group. This intervention would involve awareness of vulnerability, adapting to limitations at home or work, and the difficulty of reintegrating into routine life (Fawzy 1999). It is therefore clear that cancer itself and its treatment can affect long-term health and quality of life in people who have survived the acute phase of cancer care (Lewis 2006).

### **2.2.2 Effects on sexuality**

In addition to the psychological quality of life following breast cancer, the effects of cancer and its treatments on sexuality are not usually included in plans of care (Pelusi 2006). Pelusi (2006) found that body image was related to perceived losses and influences. The losses included missing body parts, loss of monthly periods, loss of sexual sensation and, ultimately, loss of womanhood. The term 'influences' is related to the quality of the patient's relationships before the cancer diagnosis and the amount of information and control the patient had at the beginning of the disease pathway. Lindley, Vasa, Sawyer and Winer (1998) reports that two years after treatment of breast cancer and during the follow-up period of care, women had 60% less sexual interest and sexual activity, according to their own self rating, than they had before the cancer treatment. However, it is documented that many patients receiving chemotherapy do not remember having a discussion with their oncologist about early menopause, changes in sexual responses and fertility issues (Duffy, Allen and Clark 2005). This could be related to the ability or inability

to recall all the information received at the consultation. Issues surrounding sexuality would seem particularly pertinent in the context of cancer care, since the more common treatments for cancer, such as surgery, chemotherapy, radiotherapy, hormone therapies and/or biological responses, can impact upon sexuality (Ganz, Desmond, Belin, Meyerowitz and Roland 1999). Chemotherapy is a systematic treatment associated with the side effects of ovarian toxicity resulting in premature menopause (Knobf 1998), infertility (Mc Coy 2004) alopecia and altered body image (Turner 2004). In the field of breast cancer women whose disease is oestrogen/ progesterone receptor positive are all treated adjuvantly for five years or maybe even more by hormonal manipulation. Tamoxifen has been the drug of choice and can cause irregular menstrual cycles, oligomenorrhea, or amenorrhea. No articles have been published about sexual function or response in women with breast cancer treated by aromatase inhibitors (Pelusi 2006). Body image and sexuality can be greatly affected by cancer. Many women come into the oncology setting with an already poor body image or diminished sexual function. An organized approach is crucial to assess patient need and advise accordingly (Pelusi 2006).

Many health care providers focus on follow up for cancer recurrence but not for late effects of cancer or its treatment. During the follow up period, cancer is more like a chronic condition. People may be free of disease, or they may have chronic difficulties associated with it or its treatments, as discussed above (Lewis 2006). At an American conference the attendees emphasized the need for a paradigm shift from illness orientation to a wellness approach. There is a need for education to assist patients with the transition from acute treatment to follow-up, from being a patient to being a survivor and to become an active person (Lewis 2006). Following a cancer diagnosis patients engage in various coping behaviours to maintain or restore their emotional well-being (Stanton 2006). Interestingly, one way by which individuals cope with a stressful life event is to derive some positive

meaning from the experience. People may change their personal priorities and their views of themselves to find meaning in their cancer experience. Retrospective studies report patients as having a greater appreciation of life, changes in self perception, improvement in close relationships and altered life priorities (Fredette 1995) (Landmark, Strandmark and Wahl 2001) (Lampic, Thurfjell, Berg, Carlsson, and Sjoden 2003).

## **2.3 SOCIAL CONSTRUCTS**

A number of key social constructs can be seen to shape both the cancer services and the experience of women in receipt of these; key constructs informing this study are the relationship that is enacted between professional and patient, health, healthcare and patienthood.

### **2.3.1 The relationships between professional and patient**

The physical impact of a cancer diagnosis and its treatments, in addition to the psychological distress and, in some cases, reprioritising of life, causes different types of behaviour. These behaviours will also depend on where the patient is on the cancer pathway. Apart from its implications for the patient, the role of the clinical team and the perceived behaviour of team members affect a person's experience of health and illness. Kennedy (2003) identifies the traditional approach to care as been based on the concept of expert knowledge. This expert knowledge appears to be traditionally the property of doctors but not of patients. Therefore, on the basis of this knowledge, medical staff make decisions about patients including investigations, treatment and the care they should receive. The causes of illness range across a spectrum of social processes whether by 'structural' factors like environment or by behavioural factors such as smoking or lack of exercise. In addition to these differences the way social groups behave when they become ill and the impact of these behaviours have on their care and recovery underpins how we develop services (Brennan 2004).

The medical profession sees itself, and is seen by others, as being expert in understanding and managing disease. The clinicians appear to have power as it is their duty to explain choices in treatments. Failing to do so would be falling foul of the General Medical Council regulations (GMC) (Chinthapalli 2001). However, in the light of episodes such as the Alder Hey post mortem examinations and the Dr Shipman cases, many want the balance of power to move away from doctors and pronouncedly in the direction of the patient (Canter 2001). However, power does not move as easily as that. Furthermore, power - both coercive and charismatic power - includes reward (Canter 2001). Each clinician uses each of these versions of power to develop his/her own style and these traits are difficult to quantify. A charismatic doctor may do great harm to a group of patients who are grateful to him /her. The report on Dr Harold Shipman (Shipman – The Final Report 2005) illustrates such a point (Canter 2001), although power can be seen as far more complex than this. Lukes (1974) describes three descriptions of power, the first being where one person forces another to take a particular action; the second being where one person controls the agenda in any interaction with another and the third being where one person controls the world as seen and experienced by another. Thus it could be argued that even when the patient makes a choice, this is firmly based in the biomedical model. Chinthapalli (2001) lends weight to this argument by explaining that it is the doctor's duty to influence the patient. She/he is obliged to explain choices and failing to do so would fall foul of the GMC regulations. Obviously the doctor can only explain the choices, as she/he understands them and therefore must keep abreast of latest research. Chinthapalli (2001) explains that the patient has the option to seek a second opinion from another clinician. Canter (2001) points out that there is no place for other models such as alternative medicine. Nevertheless, Chinthapalli (2001) explains that patients do not expect information on alternative treatments but that these therapies can be used if they wish. Conventional medicine has been scrutinized carefully for its effect and is proved to have

benefit. He also goes on to explain that doctors give information as impartially as possible but that doctors are human and will inevitably be slightly biased by their own views, beliefs and attitudes. Lukes' (1974) perspective of power is concerned with the outcome of that power. This shift of power is indicating that people have a freedom and liberty. Freedom is achieved by putting into place practices to promote autonomy and therefore has elements of control within it. Foucault (1982) viewed such practices as offering power relationships to a minimum of domination and saw power as part of all relationships.

Canter (2001) suggests that health professionals should be taught to keep some basic frameworks in mind to enable them to be more sensitive to power. Furthermore perhaps there is a need for a more in-depth debate that goes beyond the naïve idea that power can be 'handed over' since medical knowledge itself is at the centre of this discussion. The difficulties of handing over power is the asymmetry of knowledge as well as the dilemma as to whether the NHS is able to cope with this shift and give patients what they want in light of the ethics of taxation. This power shift may incorporate using untested therapies if the patient wishes to receive this. Where does that leave institutions such as NICE and evidence based medicine (Dingwall 2001)? The Internet offers choice; it enables patients to gain knowledge about disease and treatments, which may be otherwise denied. It appears to be particularly well utilized by people with cancer (Sharp 1999). Therefore power is a double-edged instrument and healthcare professionals need to be aware of this (Law 2001).

The internet is a fast growing medium of information and can offer hope for people with life limiting illness that focus their hopes on new treatments. However, research on media and internet information shows that it can give patients a confused picture, that the public may be prey to unscrupulous marketing, that public expectation may outstrip provision (Coiera 1996). It also draws attention to the poor quality of much of the information, and the

danger of an "inverse information law" whereby those, who are in the greatest need of information about preventable or treatable conditions, are least likely to have access to new technologies (Coiera 1996). There is little empirical research on how people with serious illness use information from the internet. There has been one qualitative interview study of internet use among people with HIV infection or AIDS (Reeves 2001). The internet extends the scope of the best stocked medical library, through access to knowledge of how people have experienced cancer as well as providing the medical information. Health professionals as well as patients stand to benefit from this, but, as yet, the internet is rarely used by people who are socially disadvantaged. Unequal access to the internet may increase social class divisions in health care, but this is not inevitable (Ziebland et al 2004). Indeed, in one UK study socially deprived respondents said that they were more inclined to use the internet than more prosperous ones (Mead, Varnman, Rogers and Poland 2003). This will also be encouraged by the development of Macmillan funded information centres in hospital and local communities.

Patient decisions regarding treatments are not solely between the doctor and the patient. Patients may consult several doctors and the patient's world of discourse outside the consultation – a scenario which involves social, economic, religious and cultural factors (Nestral 2001). Dickinson (2000) talks of 'concordance', which suggests that at the centre of the doctor/patient partnership is honesty, but Teasdale (2001) points out that this does not address the imbalance of power and the personal attributes of individual doctors and their powers of persuasion. There is also evidence that there is a lack of choice because it suits the power model. For example, the issues around referral, to be discussed later, maintains the medical power. Women are not able to self-refer to gynaecological clinics; patients with injuries cannot refer to physiotherapists within the NHS. This imbalance of power disempowers people. A shift in the balance of power is extremely complex. Within a consultation the medical team should strive to have a mutual relationship in which



patients understand all of the issues regarding their treatments and, if that aim is met, both parties should be satisfied. Even achieving this is not easy, in the present NHS, when each consultation is only of a few minutes' duration (Chinthapalli 2001). In the field of oncology the implementation of CNS posts has assisted with this objective, so patients have time to assimilate information and the CNS assesses other influencing factors, such as social support, as well as the psychological and spiritual aspects of the person (Pine, personal communication, 2006).

### **2.3.2 Defining Health**

There are many models of health, each having different consequences and implications for health. The medical model views health as the absence of clinical disease (Helman 1981). It is this utilitarian principle, which underpins government policy of the greatest good for the greatest number. This principle is often interpreted from opinion polls and does not cater for those people with considerable need and whose numbers are small (Small et al. 2000). The emphasis is on cure rather than prevention and on the treatment of an individual rather than of a social condition. The alternative is the social model of health commonly associated with the World Health Organisation (WHO) which defines health as

*“...a state of complete physical, mental and social wellbeing and not the absence of disease or infirmity.”*

(Seedhouse 1986 p31).

This model focuses on health in the social setting and promotes the idea that need is not an absolute state but an absence of quality of life, and views, therefore, health as being more than the absence of disease. When disease is present this model proposes that it is not just the treatment of the disease but discernment as to whether quality of life has been enhanced that is important. There is a variety of problems associated with social definitions of health needs and the priorities of the NHS. There is the argument that the

NHS is unable to cope with the wider definitions of health including the different social structures, which can lead to ill health with the paucity of resources at their disposal. There appears to be two main divisions described by (Canter 2001) firstly, medical knowledge, such as path-physiology and the intended effects of treatments and secondly, the individual holistic knowledge that patients have about disease and about the impact it has on their lives. However, there are changes in perceptions of health and in approaches to healthcare, including the recognition of the importance of biological, social, spiritual, cultural and psychological factors (Hewitt-Taylor 2004).

The development of patient involvement, which allows the patient to choose to be involved in care, should be seen to provide a holistic approach to care. However, McQueen (2002) argues that this may be detrimental to patient care. For example this approach may result in individuals undergoing unnecessary investigations, which may cause harm. This again adopts the biomedical model in contrast with the more holistic approach of healthcare, which includes social, emotional, psychological, spiritual and cultural aspects of health as being important. The main research regarding breast cancer follow-up appears to indicate no physical benefit (The Grupos Interdisciplinaire Volutazione Interventi Oncologier GIVIO investigators (GIVIO) 1994) including the use of routine scans and blood tests and it clinically assumes the biomedical model regarding benefit. However, the psychological benefit of attending clinics is convincing (Pennery and Mallet 2000).

In the context of breast cancer care there is a need for follow-up for different reasons as for different users. The formulation of a social definition of health will incorporate the complexities of a cancer diagnosis in relation to the psychological and social aspects of care as well as the clinical prevalence of the disease. In consideration of a social definition of health the process of 'being sick' and its impact on the person, on the clinical team and on society requires reflection.

### **2.3.3 Defining the patient**

The process of becoming a patient is one of negotiation. It may take place between professional and potential patient or it may involve others. The process of becoming and being a patient serves as part of the definition and maintenance of professional boundaries with the rest of society (Hugman 1991). It is thought that the medical profession exists for the benefit of patients. However, there is an altruistic dimension to the medical profession by which medical and nursing practice meets the needs of the clinicians as well as the service user. This impacts on the relationship between professional and patient and suggests that the professional seeks control over the patient and predicates the ability to define what a patient is and should be (Wilding 1982). This power has become a focal point of discussions in many groups of people who recognize the impact this power has had on their lives (Elder 1997).

The need for 'caring' suggests incapacity to participate fully in everyday living. Parsons (1951) determined that incapacity as the sick role. Parson's describes four main themes: Firstly, that the sick role gives exemption from social responsibilities; secondly, that the sick person needs help from a competent practitioner; thirdly, that the sick person must get well, and finally, that the sick person must co-operate with procedures towards getting well. The exemption from social responsibilities and the need for expert help allow these privileges on condition that the patient recovers and co-operates with treatment. (Parsons 1951). In accepting this role power is given to others, in particular to doctors, in defining who is and is not sick. Parsons describes this as socially desirable because it sets limits on the role and provides an incentive to recover. The sick role serves to discourage the secondary gains of illness and prevents a deviant subculture of sickness, emanating from the privileges of opting out! There have been many critics of Parsons' sick role. Williams (2005) highlights the lack of acknowledgment of chronic conditions, the needs of the

elderly and infirm and the inability of these people to recover from illness. They are therefore not included in Parsons' sick role. The needs of this group are not met within Parsons' framework and, as they are unable to 'get better,' the privileges incorporated in the sick role are not afforded to them. Many may view this as a lack of will to recover and define this as deviant. The lack of power within these groups allows this deviance to be contained and even punished rather than being seen as the reason why and as needing support to improve quality of life. Throughout the follow-up period patients remain in this 'sick role'. From the relevant literature it would appear the reassurance following a cancer diagnosis is important for patients who attend the hospital (Pennery et al. 2000) and the maintenance of this ritual allows for the dominance of professionals within the health care system and allows for a manifestation of power and self-esteem among competing professionals.

Wolinsky and Wolinsky (1981) question such factors as race, culture, gender and income and their influence on professional responses. Wolinsky et al. (1981) go on to suggest that less powerful groups may use the sick role to cope with social failure. However, in doing so they are accepting power from those in authority who define what social failure may be. Male white middle class professionals often exercise this power, despite the fact that consumerism allows for more choice today. Hugman (1981) argues that this concept remains and believes that these people are more likely to be black and/or female, to have a long term illness or a disability or simply to be old.

In the context of the sick role this concept of deviance provides the basis of power exercised by the caring professionals. This power expects service users to comply with treatments and patients expect professionals to give instructions so they can 'get better'. Canter (2001) explains that the reality is more complex and that subjects such as coercion, charisma, rewards for actions, legislation and knowledge base play a part in the exercising

of power. This will be discussed in depth later in the chapter. Entwined in this complex mire of health and illness is the long term nature of breast cancer treatments and the key issue of survivorship. Many patients require long term treatments for five years or longer and require follow-up monitoring and investigations in case of cancer recurrence and side effects (Dixon and Montgomery 2008). Much has been documented regarding the psychological support required for patients following a diagnosis and treatments for cancer. The definition of illness and health is more complex than first thought and the transition from illness to health - survivorship - requires clear sign posting and individual patient/doctor flexibility to make that transition.

#### **2.3.4 The nature of medical care**

In medical knowledge there is a degree of uncertainty, which may cause strain and tension within the professional relationship. The new paradigm of evidence-based medicine should dispel uncertainty but has in fact brought to the surface fundamental uncertainties about the nature of good clinical practice. Evidence based medicine requires the combination of scientific facts with value judgments and the costing of treatment (Saarni and Gylling 2004). It appears to be divided into two categories. One describes evidence-based medicine from an epistemological perspective and another from a practical viewpoint.

The development of sentinel node biopsy has brought some of these challenges into the breast cancer arena. The issues of micrometastases and whether these should influence treatments and cancer management have been discussed at length between MDTs and at national educational meetings. In cancer networks there does not appear to be consensus among consultants regarding treatment plans and the long-term complications or side effects, which may influence follow-up care. Hunter (1996) suggests that evidence based medicine can oversimplify the complexities of the situation, thereby claiming certainty

where none exists. There is an important question as to whether there is an evidence based medicine solution to all medical problems (Saarni et al. 2004). If the answer is 'yes', the best available evidence may be professional intuition.

Regarding the issues of micrometastases some clinicians feel that this will effect survival and therefore change treatment management. If the answer is 'no' and there is not always evidence that signifies a certain level of knowledge, such as trial data indicating statistical significance, then patients need to be aware of this. Medicine is pragmatic and what matters is that the patient is treated in the best possible way. The evidence-based medicine becomes synonymous with good clinical practice. When treatments are being audited for cost effectiveness, professional intuition is rarely regarded as evidence. The same is true of the individual patients' own experiences, opinions and preferences which revert back to the biomedical model.

Sickness exempts from social responsibility and forfeits a certain degree of power. Chronic illnesses have not been included in Parson's (1951) framework and therefore these powerless groups are not supported to recovery once their physical illness has been treated. In order to develop services to incorporate this social aspect of caring the relationships developed over time between medics and patients requires teasing out. The vulnerability of newly diagnosed cancer patients, the ability of the team to treat successfully, the expectations of patients and the intricate responsibilities of the MDTs are all paramount to developing services.

There are also differences between the levels of power within the MDT. Some professionals are regarded as having more knowledge and expertise and therefore one of the crucial components of the process is the status of the person making the referral (Smith 1980). Where a profession has uncertain status in relation to the powers of

referral, then the possibilities of disagreement are increased. Nurses have their patients defined for them by doctors. This gives the doctor the power to diagnose and prescribe not only medication but also tasks for nurses to complete. Defining the patient's needs also defines the caring professional's role and this is established from training and past experiences (Hugman 1991). Where the knowledge of the clinician is strongly demarcated, the action of the professional will carry greater legitimacy with the service user. Hugman (1991) quotes:

*"You know best, you're the professional"*

p128

It is also very difficult for the patient to exercise choice as to who provides nursing care. Senior colleagues, agencies or monthly rotas, allocate patients to nurses. Even in private practice the relationship may be with an institution or with a professional such as a doctor. This again places the power base at a higher level for doctors than for nurses and patients are unable to exercise choice.

Calinas-Correia (2001) writes that the medical view implies that the upper hand is with the doctor and this is very difficult to change without destroying the core of medicine itself. The paper goes on to deny that the legitimacy of medicine to interpret a patient's history and prescribe medical intervention is wrong. An expert is defined by Calinas-Correia (2001) as a person in authority and with authority comes power. It does not matter what that authority is, whether fire alarms or neighbourhood watch, but that those who fail to follow authority incur guilt and its consequences. In the article no account appears to be taken of the social, religious or other influencing factors. Calinas-Correia (2001) uses as an example a lung cancer diagnosis after years of ignoring a doctor's advice regarding smoking and goes on to explain that there is a difference in power between doctors, lawyers and engineers or teachers. It isn't the power bestowed on the person but the

social pressure to surrender to the expert. One can ignore advice from others but no one can be properly sick without the sickness being legitimated by a doctor, which ties into the Parson framework. In discussions regarding shifting power between a patient and doctor it may also be between patient and others. These others may be patient's loved ones, peers, advocates, solicitors and employers. It is this same group who will maintain the power and not the doctor. Calinas–Correia (2001) states that the power does not lie with the patient but with these others who will promote the doctor's power by pursuing conformity to the advice which the doctor, as an expert, has given.

### **2.3.5 Developing the role of nurses**

In the field of cancer clear nursing boundaries are being diluted. The National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Primary Care want to reduce the variations in referral times from primary care to specialist investigation for people with suspected cancer. There are recommendations on the diagnostic and referral process for a wide range of cancers, including lung, breast and skin cancer. The guidelines take into account new research and evidence published since the previous publication of guidelines in 2000. These guidelines will be a practical tool in encouraging nurses to play a greater role in clinical decision-making and will help patients with suspected cancer to be detected earlier. This change begins to encroach upon the doctor's role of referral. Since August 2004 junior doctors have come under the European working time directive, which means they will be limited to an average working week of 58 hours. This year, 2009 they are only allowed to work a 48-hour week. It is thought that junior doctors will be completely or partially replaced by nurses at nights and weekends at more than a dozen English hospitals as part of a government drive to cut junior doctors' hours (Pickersgill 2001). Along with the European directive there have been extensive developments within the nursing profession in the United Kingdom (UK).



A proliferation of nursing roles has paved the way for nurses to practice at higher levels under such titles as “nurse practitioner”, “clinical nurse specialist”, and “consultant nurse” (Department of Health 1999). Defining the role of a clinical nurse specialist, as with other newly defined roles, has been an issue of debate (Castledine 1996, McSharry 1995,) although there is agreement that specialist nursing maintains patient care as a primary focus, and involves the provision of expert advice to both patients and health professionals, the promotion of research, and the development of practice guided by evidence from research (Yerrell and Reed 1997). With this expansion of nursing roles comes new challenges. Innovative roles are likely to be stressful because of the inherent difficulties involved in establishing a new post (Read et al. 1999). Moreover, the absence of standardized roles (Read et al. 1999), combined with the current lack of professional self-regulation, may lead to nurses taking on roles for which they do not have the optimum training or experience. Papenhausen and Beecroft (1990) propose that without appropriately advanced preparation, complete role fulfillment will not be possible. Nurses need to be involved in the development of their profession to ensure that they are not controlled within a medical model. The services need to be nurse directed and have the engagement of key nurses in Trust organizations and sufficient education of nurses with curricula which incorporate the new holistic approach. In order to meet these changes in nurse education and practice nursing careers must respond by not working in isolation to meet the changing needs of complex patient groups and provide a high level set of clinical skills and understanding of the ability to care (DOH 2006a).

Nursing can be seen to provide the delivery of key caring, comforting and technical skills (Johnson 1999), and Aranda (2001) discusses the promotion of the nurse/patient relationship and its importance in being the foundation of nursing practice. In specialist practice the nurse is experienced and able to reciprocate and self-disclose in a safe and therapeutic manner. The nurse/patient relationship is vital and allows intimacy which is

now difficult for other nurses to obtain due to the fast turnover of patients, an increase of day care and short hospital stays. This aspect of caring is central to nursing (Dowling 2006). Nursing has moved away from an emphasis on hygiene and towards a humane concern with communication. It is sociology that is central to this humanizing change in nursing care, enabling the nurse to relate to the whole person and to the physical and psychological impact of illness.

The holistic approach is presented as both necessary and sufficient to the successful integration of diverse knowledge. This is pertinent to breast cancer and the arena of follow-up. In practice, however, its ability to provide such a framework to bring together disparate disciplines into a cohesive team is more apparent than real. Mulholland (1997) claims that the difficulty lies in the different sources of sociology, physiology, psychology and philosophy and the ability to ascertain specific objectives to meet these subjects in nurse education. Scientific problems are different to moral problems. For example, the experience of black women with illness and the biological accounts of illness have led to an inevitable consequence. The holistic approach gives little or no attention to some of the knowledge and theoretical difficulties but collects explanations, which are rarely examined. Nursing requires critical debate regarding the holistic approach and, as these different aspects of care are incorporated into the profession, it requires frank discussions of aims, needs and choice and how an effective and holistic approach can be achieved (Mulholland 1997). To meet the needs of patients a holistic approach is paramount to the improvement of care by a rigorous dialogue between nursing and sociology, taking full account of the inherent complexities of nurse education, which should include sociology as a separate discipline to offer nursing an invaluable source of reflexivity. If nurses are to take on new roles, as stated above, education is needed to support this type of care.

A user is someone who is directly receiving services relating to a particular condition or

need. However, a user can also be someone who has received services and may not need these services in the future (Gott, Stevens, Small and Ahmedzai 2000). There are also people who are involved in cancer care, work within the specialty and have expert knowledge. With the combination of users and professional there is a danger that the professional will take over the group and dilute the users' perspectives as derived from their experiences. The richness of perspectives based on experiences may be lost and this will have an impact on service provision.

The involvement of patients also needs to be clarified as it appears to have different levels such as patient decision making in the context of treatment choices; care delivery and service planning (Small et al. 2000).

## **2.4 SUMMARY**

The impact of a diagnosis of breast cancer to a patient and her family is complex and multi-faceted requiring psychological and social components of care. The nature of health and illness underpin the way in which services are utilised and shape the model of service delivery. The relationships between the patient and the professionals affect the patient experience. Traditionally the doctors have expert knowledge and make clinical decisions about patients. This expert knowledge provides a basis of power which expects patients to comply with treatments (Canter 2001) coupling with the incongruence of uncertainty of illness and the patient expectation of certainty from evidence based medicine. This may cause strain on the medical profession and patient/doctor relationship. The importance of cancer treatment is paramount and very much in the medical model of care (Canter 2001). However, different definitions of health also incorporate the importance of biological, social, spiritual, cultural and psychological factors (Hewitt-Taylor 2004). In developing breast cancer follow-up services the formulation of a social definition of health will

incorporate the complexities of a cancer diagnosis and the key issues of survivorship. Nursing is in a good position to provide key aspects of caring with the support of the MDT but ownership is needed by all members of the MDT. Critical debate regarding the aims, needs and choice of holistic care need to be formulated and measured within the MDT to acknowledge patients as individuals and assist with cancer rehabilitation. The diagnosis of breast cancer, its treatments and side-effects impacts on so many aspects of living for patients over a long period of time. The MDT need to be aware of the ongoing nature of these complexities and the nature of the doctor patient relationship and how that influences patient decision making.

## **CHAPTER THREE**

### **LITERATURE REVIEW**

#### **3.0 INTRODUCTION**

The literature review strategy initially focused on breast cancer incidence and survival, treatments and follow-up services, narrowing to a search for papers concentrating on cancer follow-up, nursing interventions and patient/professional relationships. In order to maximize the range of data collected for the review, the research strategy encompassed treatment discussion with senior cancer clinicians and journals to review, manual journal searches, Internet web sites and a number of computerized databases: Biomed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, British Nursing Index and the Department of Health. In addition a search of reference lists from retrieved papers was also undertaken and papers posted from the British Library with permission.

The key words used for searches were 'breast cancer incidence', 'cancer follow-up', 'power and caring', 'nursing roles', 'nurse led follow-up', 'patient satisfaction', and 'preferences of follow-up'. The search strategy retrieved literature reviews, discussion papers and evaluation of follow-up practices.

#### **3.1 BREAST CANCER SURVIVAL**

Analyses of incidence trends in England and Wales show a marked overall increase since national coverage of cancer registration was effected in 1962 (Quinn et al 1995). The rates of increase changed when the national screening began in 1988. Between 1979 and 1987 the rates increased at approximately 2% per annum but between 1988 and 1992 the annual rate of increase rose to nearly 4.5% (CRC 1997). As stated in the introduction in the UK in 2006, 293,000 people were diagnosed with cancer and in 2007, 155,484 died of

the disease ([www.cancerresearchuk.org/statistics](http://www.cancerresearchuk.org/statistics)). Currently one person in three living in the UK is liable to develop cancer during his/her lifetime. Regional variations reflect a relationship between poverty and breast cancer risk, with higher incidence in the less deprived areas. This higher incidence is associated with HRT, access to screening, differing life styles also possible late referrals from PCTs (Mayor 2009). The prevalence of cancer has also increased, as women diagnosed in 2005 will survive longer than their counterparts diagnosed in the 1970s and 1980s. However, improvement of survival does not indicate that breast cancer has changed biologically but that changes to diagnosing and managing breast cancer have reduced the incidence of relapse and death (Jones 2005). This could thus be attributed to early detection through the national breast screening programme and/or the use of systemic treatment after surgery to reduce micrometastases. The Cancer Reform Strategy's second annual report highlights regional variation in cancer outcomes and services (Mayor 2009). The findings show an increased reduction on overall cancer mortality but major differences in survival rates for different primary care trusts. This year there has been a further fall in cancer mortality with the latest data showing a drop of almost 20 percent since 1997 and considerable improvements in the survival rates for breast, colon, rectum and prostate cancer. To date, the health service has used figures based on five-year survival, there will now be a focus on one year survival. One-year survival - that is surviving a year after cancer is first spotted - is key in regard to measuring early diagnosis because death before the one-year mark is likely to be due to the disease only being identified at a late stage. It maybe in Primary Care Trusts where work needs to be focused and earlier referral of symptomatic patients (Mayor 2009).

Olsen et al (2005) report a 25% reduction in the mortality rate of breast cancer patients who were invited for screening in Copenhagen. The study covered ten years of screening and compared the population during screening with historical and national controls. There

were significant results after six years of follow-up, which were not due to systematic treatments since treatments in Denmark had been standardized across the country since 1977. In the UK the reduction in mortality could be due to both earlier presentation of symptomatic breast cancer in some regional areas and the uptake of symptomatic treatment with adjuvant therapies (Blanks, Moss, McGaham, Quinn and Babb 2000), (Mayor 2009). Even though there was better breast cancer survival in the United States between 1990 and 1992 than in Europe, this could be attributed to stage of the disease at presentation. Once stage of disease has been accounted for, screening has no influence on survival (Jones 2005). More importantly for both screening and for symptomatic patients, adjuvant chemotherapy and hormonal manipulation is likely to play vital role in improved survival (Jones 2005). The Bonadonna study (Bonadonna et al. 2005) found a 21% reduction in relative risk of death from all causes in keeping with the overview analysis by the Early Breast Cancer Trialists Collaborative Group (EBCTCG). They investigated the benefit of adjuvant chemotherapy of Cyclophosphamide, Methotrexate and 5-Fluorouracil (CMF) in thirty years of follow-up in the context of improved survival (Jones 2005). The Bonadonna (2005) study indicated a benefit from systematic hormonal and chemotherapy treatments. In addition, current chemotherapy regimes used in breast cancer are more advanced, such as the use of anthracycline and taxane based treatments, and so they are more effective (EBCTCG 1998). The above two studies by Olsen et al. (2005) and Bonadonna et al. (2005) show improved survival from adjuvant systemic treatments and the diagnosis of small node negative cancers but, as stated by Jones (2005), neither approach affects incidence or the diagnosis of breast cancer as this can be still devastating even with low-grade cancer. Breast cancer is now recognized as a chronic illness that can recur even after 20-30 years. Survival has improved and women are living longer on long-term adjuvant hormonal therapies. Their follow-up care needs to be managed and at present follow-up protocols vary widely and are not always evidence based. The traditional mode of breast cancer follow-up needs to be re-visited.

### **3.2 BREAST CANCER FOLLOW-UP.**

In an era of increasing financial constraints, physicians are being forced to critically re-evaluate a range of clinical practices (Tomiak et al.1993). Routine follow-up programmes following primary therapies for breast cancer vary widely from centre to centre, and the evidence base for this remains unclear although they are the subject of numerous retrospective analyses. Few of them however, have been prospectively evaluated and it is the clinical benefit to follow-up in detecting recurrence either loco-regional or systemic that is appraised (Dixon and Montgomery 2008). Other studies have evaluated the importance of follow-up for the women (Pennery and Mallet 2000), (Allen 2002) and whether other members of the MDT could manage breast cancer follow-up (Hammond, Chase and Hogbin 1995). Other studies have reviewed the role of the GP in follow-up care (Grunfeld, Fitzpatrick, Mant and Vessey 1995), (Grunfeld et al. 2006). However, no study has reviewed the views of all the key stakeholders together and considered the issues of survivorship following a diagnosis of breast cancer and the long term impact of treatment and whether these elements of care are addressed in breast cancer follow-up as it is currently delivered.

#### **3.2.1 Surviving breast cancer**

Survival is related to many factors including size of tumour, presence of metastases in the axillary nodes and distant metastases. For all women (aged 15-99) diagnosed in 2001-03, 72 per cent are likely to survive for at least twenty years. The survival rate is still increasing more than ten years after initial diagnosis, however, and 64 per cent are likely to survive for at least twenty years. This reflects the current excessive rate of mortality among women with breast cancer, many years after initial diagnosis, although long-term survival from breast cancer has improved significantly over the past ten years (Cooper and Westlake 2008). Overall, women diagnosed in the early 1990s had about a 54 per cent



chance of surviving for ten years and a 44 per cent chance of surviving for 20 years. But ten years on, estimates of long-term survival for women diagnosed in the early years of this century show an improvement of 17-20%. The improvement is slightly better for women aged 50-69 years. In contrast, the predicted improvement in long-term survival for women aged 15-49 years at diagnosis is much smaller, at about 13-14 percentage points, and the data for 2001-2003 suggest they will have long-term survival rates that are lower than for women aged 50-69 at diagnosis. This therefore may have an impact on the organization and developments of follow-up (Cooper et al. 2008).

Guidelines from the National Institute for Clinical Excellence (NICE) in England and Wales (2002) state that the aims of breast cancer follow-up are to detect and treat local recurrence, to deal with adverse side effects of treatment and to provide psychological support. The guidance suggests that the aims can be met by two to three years of follow-up and that long-term follow-up is ineffective and unwarranted. It is difficult to understand NICE (2002) that one of the aims is to provide psychological support and deal with adverse effects of treatment when some treatments continue for five years or longer and it is difficult to quantify when people have recovered psychologically from the diagnosis and treatments of breast cancer. What is more, users have not been asked to comment on this change of practice. A cancer diagnosis invokes fear for many people and it appears that there are different periods of time during the patient journey that anxiety and distress is heightened for patients (McKinley 2000). In the follow-up stage women are dealing with the physical effects of treatment – fatigue, hair loss, menopausal symptoms, the risk of lymphoedema and the loss of or decreased libido (Stanton 2006). There is a paucity of data as to whether these physical effects are addressed routinely or if they are an important aspect of the follow-up regime. In addition, with the introduction of extended adjuvant treatments such as aromatase inhibitors and Herceptin, many women may not have anticipated the length of treatment and some of the side effects attached to these

treatments, which may also caused additional distress. Once treatments are completed women do not have to focus on hospital appointments and medical treatment and this may leave 'head room' for the psychological impact of treatment and diagnosis and lead to the reflection of mortality in relation to this illness (Lethborg, Kissane, Burns and Snyder 2000). This maybe at a time when the patient's family support is much less and the proposed change to follow-up care to discharge from the clinical area could be a potential source of distress.

There is no advice or guidance for surveillance mammography, as they believe the yield from mammography is low and advises cancer networks to write local evidence protocols around the timing of mammograms. However, Montgomery et al. (2007b) found 56 local recurrences detected by mammography and those recurrences had better survival than self detected.

In the USA there has been twenty years of work by the National Coalition for Cancer Survivorship (NCCS), the Office of Cancer Survivorship (OCS) of the National Cancer Institute (NCI). The Lance Armstrong Foundation was founded in 1997 when Lance, a world-winning cyclist was diagnosed with cancer and set up this organization to assist with survivorship needs. Much of the impetus towards acknowledging and addressing the many unmet survivorship needs has been driven by this foundation. ([www.livestrong.org](http://www.livestrong.org)). The foundation has contributed ten million dollars to cancer survivorship and research. The American Society for Clinical Oncology (ASCO) established a Survivorship Advocacy Group that works to ensure that all ASCO programmes consider survivorship issues and guidelines are produced for patients free on line regarding the late effects of treatment (Lee et al. 2006). This is incorporated into their care and patients are encouraged to avail of this information regarding side effects and to report to the team. Research has been funded across disciplines around survivorship issues and through partnerships with the

USA Food and Drug Administration (FDA) to discuss endpoints for drug approval.

The basic components of routine follow-up in the UK, most commonly present, are regular history taking, physical examinations, annual mammography, blood test, chest X-ray, bone scan and liver ultrasound (Tomiak et al. 1993, GIVIO 1994, Tomin et al. 1987, Schapira and Urban 1991).

The core objectives of follow-up programmes have included

1. The early detection and treatment of recurrence.
2. The early detection of new primaries.
3. The evaluation of primary and adjuvant therapies, particularly for patients enrolled in clinical studies.
4. Monitoring for long-term complications and therapy.
5. Patient rehabilitation and psychological support.
6. Family and risk counselling. (Tomiak et al. 1993).

### **3.2.2 Early detection of local recurrence: impact on survival.**

Reflecting on the above objectives the main purpose of follow-up is summarised as the earliest possible diagnosis of a relapse with a view to applying a curative second line treatment, Dewar (1995) asks how often we achieve these aims.

Much has been written about the value of follow-up for detection of breast cancer recurrence. (Tomin et al. 1987 Schapira et al. 1991, Wertheimer 1991, Koinberg Fridlund, Engholm and Holmberg 2004, de Bock, Bonnema, van Der Hage, Kievit and van de Velde 2004, de Bock et al. 2004a). It has been debated by several authors as to the possibility

that traditional breast cancer follow-up programmes may have little or no benefit for patients. The main conclusion emerging from the published literature is that, despite the lack of confirmed evidence of the value of screening, the value of routine history, physical examination and yearly mammography appears to be accepted by most clinicians (Dixon et al 2008). These investigations in combination make for the detection of local recurrences at an early stage for which curative salvage therapy is available (Dixon et al. 2008). The evidence does not include any prospective data to recommend any particular method of follow-up but in the absence of such data the only available evidence comes from retrospective audits of patterns of relapse and the way these recurrences were detected. Montgomery and colleagues have reviewed breast cancer follow-up extensively and published new data regarding recurrence patterns and methods of detection in thousands of patients (Montgomery et al. 2007), (Montgomery, Krupa, Cooke, (2007a), Montgomery, Krupa, Cooke, 2007b). The conclusions from this large body of retrospective evidence are that the value of routine clinical examination is limited. Patient self examination detects more than twice the number of recurrences and the use of an annual mammogram achieves the same objectives as the three yearly national screening programme in the general population. However, there is a paucity of prospective data in breast cancer follow-up and there is a need for a randomized control trial to provide true evidenced based guidelines (Donnelly Hiller and Dunn 2008). Grunfeld et al. (2006) demonstrated with a randomized control trial the benefit of annual mammography and of a review by GPs a year after diagnosis. However, after review from The National Cancer Research Institute (NCRI) this Canadian study could not be applied to the UK NHS.

Tomin et al. (1987) present a quantitative study to determine whether routine follow-up after mastectomy for breast cancer and the detection of asymptomatic recurrence offered a survival advantage for patients. The authors reviewed the medical records of 1,230 women treated for invasive breast cancer and 248 cases of recurrence were identified.

Ninety nine out of 248 (35.9%) women had asymptomatic recurrence with 149 (64.1%) presenting with symptomatic recurrence. The discovery of asymptomatic recurrence was associated with node negative and hormonally positive disease, which had survival advantage. However, compliance with the follow-up management did not confer superior survival.

Rutgers et al (1991) analysed 4166 breast cancer patients who were followed up in accordance with a fixed follow-up schedule, not including mammography, in The Netherlands. During the 4,533 routine outpatient visits, 4116 chest x-rays and 3889 pelvic x-rays were carried out and the specialist team carried out 17,000 blood tests. In the follow-up period, 148 patients were found to have distant recurrence of whom 34 (23%) had asymptomatic metastatic disease and 114 had symptomatic metastasis. Of the 8005 x-rays 24 (0.3%) revealed asymptomatic metastatic disease and 17,000 bloods test led to the discovery of six non-symptomatic bone and four non-symptomatic liver recurrence. Screening for metastatic disease did not result in the reduction of lead-time to the diagnosis of asymptomatic metastases; the disease free survival was equal in both symptomatic and non-symptomatic patients. They suggest that local regional recurrences are often first detected at the time of clinic visits. In this series 42 of 46 loco regional recurrences were detected by physical examination during a routine visit and 37 of these recurrences had not been noticed by the patient. Unfortunately the authors did not report the clinical outcomes of these patients but neither group were amenable to salvage therapies nor, in 1989, did they have the hormonal manipulation or chemotherapies used now.

Schapira et al. (1991) reported that the early frequent outpatient clinic visits with only physical examination and an annual mammography did not improve early detection of recurrence or overall survival. GIVIO (1994) initiated a large study of intense versus

minimal surveillance in follow-up and Rosselli Del Turco et al (1994) enrolled 1243 breast cancer patients in an Italian trial, randomizing intense versus periodic follow-up of examination and mammography, and found that routine radiological and biochemical surveillance does not improve survival. Despite regular hospital visits the majority of breast cancer recurrences will present with symptoms between visits (Churn and Kelly 2001) and the value of clinical examination is questionable. In a recent audit in Edinburgh only fifteen out of one hundred and ten recurrences were detected in clinic (Dixon et al. 2008).

Tate, Clifford, Royle and Buchanan (1989), Snee (1996) and Churn et al. (2001) separated the data into two groups of patients, one treated by mastectomy and the other treated by conservational surgery. After mastectomy within these three studies it appears that between 41% and 66% of local recurrences were detected by clinical examination. Tate, et al. (1989) reported 11 (41%) patients as having developed recurrence. Snee (1996) reported 3 (60%) patients as having developed recurrence of breast cancer and Churn et al. (2001) reported 6 (66%) patients. Mammography played no part in the detection of these recurrences and the contralateral breast was not included in the research.

Three other studies discuss local recurrence in mixed mastectomy and wide local excision patients (Grunfeld et al 1996, Lees Gabos and Jenkins 1997 and Churn et al. 2001). As the population of the studies has had different surgical management, it is difficult to detect a pattern of relapse. Mammogram also plays a smaller role with women who have been treated by mastectomy than those who have had a wide local excision. However, clinical examination detected a smaller number of recurrences in these studies than in the mastectomy studies alone. Less than one third of recurrences were detected with clinical examination.

Montgomery et al. (2007b) reviewed the literature in relation to breast cancer follow-up and the investigations used. Eight studies looked at recurrence in women who had wide local excision. The data showed 38% of recurrences were detected by the patient, 30% with the use of mammography and 28% by clinical examination. Four patients relapsed but the method of investigation was unknown (Mohoney 1986; Rutgers et al 1991; Hussain et al 1995; Jack, Kerr and Kunkler 1998; Churn et al 2001; Grogan, Rangan, Gebiski and Boyages 2002; van der Sangen et al 2006; Montgomery et al. 2007b). Much data regarding follow-up has been published before 2000 and Montgomery et al. (2007a) investigated the question as to whether mammography had made a difference depending on whether it was reported before the year 2000 or not for women who had breast conserving surgery. Interestingly, literature published before 2000 shows patients as having detected 39% of recurrences whereas the literature published after 2000 shows that 37% of patients detected recurrence. The recurrences detected with clinical examination and mammography show a reversal of that pattern. Before the year 2000 15% of recurrence was detected by mammogram and 46% in routine clinical examination. After 2000 40% are mammographically detected and 15% in routine clinical examination. There is a trend that the more recent the published work the more incidence of ipsilateral breast cancer being detected by mammography. Further work is needed to assess this in more detail as there was overlap between the studies in terms of dates of diagnosis and relapse. It would be useful to assess the proportion of relapse diagnosed by mammogram each year in a large cohort study to confirm for analyses (Montgomery et al. 2007a).

### **3.2.3 Diagnosis of asymptomatic metastatic disease.**

Literature on the early detection of distant recurrences, based entirely on retrospective results, is unanimous that most routine investigations such as chest x-ray, bone scan, liver scans and routine bloods are not justifiable (Tomiak et al. 1993, GIVIO 1994, Rosselli Del

Turco et al. 1994 and Pestalozzi 2007). Of 7,984 bone scans performed, as part of follow-up in NSABP-B09 trial, on patients with Stage II breast cancer, only 52 (0.6%) lesions were detected in asymptomatic patients. (Wickerham, Fischer and Cronin 1984).

Rutgers et al. (1991) evaluated 4166 chest X-rays, 3899 pelvic X-rays and 17000 laboratory tests. These intensive tests detected ten asymptomatic liver and bone relapses. Schapira et al. (1991) also critically reviewed the literature regarding intensive follow-up and found that follow-up of patients with breast cancer is expensive and does not significantly extend survival. These findings led them to argue that commonly performed tests have no obvious benefit in asymptomatic patients. Furthermore, they argue that, even when new metastases are discovered in an asymptomatic patient by such tests, the interventions available will not improve the patient's survival chances compared with those of patients whose recurrences are self discovered because of symptoms.

Wertheimer (1991) disagrees with these conclusions. He writes from an informed perspective, as a clinician within the specialty, on the bio-medical ethical issues. His view is that patients are reassured by frequent contact with their oncologist. Wertheimer (1991) argues that close post-treatment surveillance has great value in that it improves the quality of life in many patients, reduces morbidity, reduces psychological distress, and may, in some instances, actually reduce costs. However, studies by GIVIO (1994) and Rosselli Del Turco et al. (1994) did not concur with Wertheimer's argument in that follow-up resulted in improved quality of life. Wertheimer argues that some patients' interventions are sometimes justified even if they are not cost effective. Renehan, O'Dwyer and Whynes (2004) conducted a systematic review and meta-analysis of randomized controlled trials of intensive compared with controlled follow-up of colorectal cancer and showed an improvement in survival. They analysed five clinical trials of 1342 patients and found that intensive follow-up was associated with a reduction in all causes of mortality



( $p=0.007$ ). The effect was more pronounced in the four external trials that used computed tomography (CT) and bloods measuring carcinoembryonic antigen ( $p=0.002$ ). Intensive follow-up was associated with significant earlier detection of all recurrences of colorectal cancer. As Wertheimer (1991) highlighted that, as diagnosis, test and treatments are improved, breast cancer follow-up may change and result in improved survival. This has been agreed by Dixon et al. in 2008. Patients now live for longer with the knowledge that they have an incurable disease. However, with new drugs breast cancer is now treated as a long-term condition.

Snee (1996) reported five patients who had relapsed after mastectomy, two were diagnosed with axilla recurrence, three had chest wall recurrence, two had symptoms, one was diagnosed clinically. There was no difference in survival rates regardless of how or where the metastatic disease was diagnosed. Van der Sangen et al (2006) studied relapse in 86 women who had a wide local excision more than five years previously, examining follow-up investigation and survival. Montgomery et al. (2007) also provided data on 110 patients who had breast-conserving surgery and between the two studies 194 relapses are discussed. Two of these relapses were detected incidentally, and these relapses occurred five years after original diagnosis. From the data there appears to be a trend towards a lower ten-year survival from original diagnosis in women whose relapse is detected clinically as compared with detection by either image or patient. However, this difference has disappeared by 15-20 years and overall there is no significant difference in survival between the three methods of detection.

The evidence by Montgomery et al. (2007) highlights the need for follow-up but does not concur with NICE and ASCO guidelines that follow-up should be for the first three to five years, although there is an increase in relapse in the first three years. The explanation for this is due to a peak in distant breast cancer recurrence and to the failure of some

researchers to record contralateral breast cancer as cancer recurrence. Montgomery et al (2007) consider the rate of relapse to be approximately 3% per year during the first two to three years, falling to 2% after three years with potentially treatable relapse occurring at a constant rate of 1-1.5% per year for at least ten years. Therefore, to meet the aims of follow-up set up by NICE to detect and treat loco-regional recurrence and not distant metastases, patients cannot be discharged at two to three years. Clinical examination only detected 13% of recurrence after breast conservation (van de Sangen et al. 2006, Montgomery et al. 2007), thus failing to meet the aims of follow-up. Mammography appears to be the most important way of detecting recurrence in the ipsilateral or contralateral breast, although the early data (Mohoney 1986) did not prove this. However, data since 2000 indicates that 50% of all treatable recurrence has been detected by mammography (Churn et al. 2001, Grogan et al. (2002), Montgomery et al. (2007a), van der Sangen et al 2006, Montgomery et al. 2007). NICE bases its recommendations for follow-up on the findings of one retrospective analysis by, Donnelly, Mack and Donaldson (2001). This data was not clear. Follow-up was for a median of three years and eleven months. Sixty seven patients who developed metastatic recurrences and 41 who developed loco regional recurrences were detected. Of the 41 loco-regional recurrences 28 were symptomatic and seven were diagnosed clinically. Two were diagnosed with imaging but not mammography, which is in complete contrast with all the other data. Montgomery et al. (2007b) reveals there are no randomized trials within the literature with power to inform the guidelines. There are ten studies in the literature that fully present the pattern of relapse after breast cancer and how it has been detected. Only Lees et al. (1997) reports on more than fifty patients and only one - Snee (1996) - has any survival data.

### **3.2.4 Women's perceptions of follow-up**

Muss, Tell, Case, Robertson and Atwell (1991) surveyed 101 women to determine their perceptions and preferences in relation to follow-up care. They also ascertained their general knowledge concerning detection of breast cancer recurrence and how clinicians investigate and report test results. They adopted a combined qualitative and quantitative approach. A questionnaire was used with thirty-minute interviews for the sample population. Data was systematically analyzed using an appropriate software package. Even though the stated aim of the study was to determine how breast cancer patients perceive and prefer follow-up care, which implies a qualitative aspect to the research, the use of questionnaires and structured interviews facilitated the collection of numerical data. This study by Muss et al. (1991) found that patients' preferences differed according to their disease stage. Twenty (43%) of women with local disease preferred 3-6 month follow-up but 10 (20%) women with metastatic disease wanted an appointment every month or 17 (35%) women wanted bimonthly appointments. Ninety two percent of patients overestimated the value of laboratory and imaging studies and underestimated the value of the medical history and physical examination thus indicating a need for information. The study by Muss et al. (1991) suggest that education about the disease and treatment can increase patient awareness concerning outcome and may be associated with significant improvement in psychological and social function. In their study 85% of women were aware of the fact that they had undergone complete blood counts, urinalysis, mammograms, bone scans and chest x-rays. Eleven patients thought mammograms were unnecessary for follow-up. Eight of these had metastatic disease and were undergoing therapy.

Pennery et al. (2000) recruited twenty four patients to ascertain their views of follow-up care by semi structured taped interviews. The interviews were conducted by a nurse practitioner who may have biased the answers, but consistent themes emerged. The

results highlighted the importance of the follow-up appointment as an event in the patients' lives. Fifteen (73%) did report anxiety before the appointment due to fear of recurrence being detected and because of an association with the hospital and bad feelings. Sixteen (67 %) expressed satisfaction with the frequency of the clinic visits and found the appointments very reassuring. Four (17%) women attended clinics annually and would have liked to come more often. They described a feeling of being 'cast aside' when only being seen annually. Pennery et al. (2000) asked about going to the GP for support but 15 (63%) did not access their GP because they felt they were too busy and lacked the specialist knowledge of cancer. Eighteen (75%) women felt that their examinations were hurried and that the investigations were not reassuring. Nevertheless, 7 (29%) of those interviewed would have liked more tests. Again the women discussed the importance of continuity and explained that they would prefer their care to be delivered by the nurse.

Previous research into patient preference for information suggests it is usually the doctor from whom the patient chose to receive information as doctors are seen as more knowledgeable. (Suominen Leino-Kilpi and Laippala 1994). However, over half of the patients suggested that a Breast Care Nurse should provide follow-up and the majority of patients supported the idea of some form of nurse-led follow-up care. McKinley (2000) highlights the effects which a diagnosis of cancer has on a woman's life and the loneliness experienced once treatment has finished and the need for someone who is aware of patient feelings to provide information. The specialist nurse may meet this need because they are seen to be approachable, available and clinically credible (Karani and Wiltshaw 1986).

Allen's (2002) study elicited the experience which women had at the follow-up, by interviewing six women. All the women interviewed gave assurance that they did not live in the constant shadow of anxiety from the diagnosis of cancer. However, they did

suggest that they experienced anticipatory concern in the immediate period prior to the follow-up appointment and that it was triggered by required attendance. This anxiety appeared to be the reason why all of the women interviewed expressed a strong desire to continue to attend clinic appointments and three out of the six (50%) would have liked to attend more frequently. All women felt that continuity was important and were not satisfied with seeing different doctors and not being seen on time.

Obviously there are implications for practice in relation to these small scale studies in that it highlights the importance of the patient voice and its role in follow-up. Women should be encouraged to take an active role in their follow-up management, and every effort should be made to educate women about the signs and symptoms related to recurrence. These themes are critical for the women who use the service. No study has investigated these views in relation to the opinions of the MDT or the GPs or to ascertain how clinical practice could change to meet the service needs and what are the difficulties and resources required in developing such a service.

### **3.2.5 General Practice follow-up**

The Cancer Reform Strategy (2007) and work published by Darzi (2007) discuss at length the changes to be made to the NHS and cancer services in order to meet the challenges of changing demographics within the population, inequities within health care and access to services. All patients with symptoms in the breast, regardless of cancer, will be seen in two weeks to develop a 'world class service', discussed in the cancer reform strategy (DOH 2007). This strategy is to speed up diagnosis and treatment of cancer. Over the years the NHS has changed, introducing a competitive element to care from different institutions. This competition brought incentives both financial and non-financial, such as peer review and public performance reporting in order to promote motivation (Dixon 2008). Now Darzi (2007) is focusing on three areas: world class care and what it looks like, the

barriers and enablers to developing this care and the development of systems to increase competition and choice for patients (Darzi 2007). Payment by results (P.b.R) has started to develop this competition but the audit commission declares it is not as effective as first thought (Audit Commission 2008). However, Dixon (2008) reports there are many important incentives in place to help increase quality and efficiency.

Primary Care Trusts (PCTs) and practice-based commissioning are improving out-of-hospital care and reducing avoidable admissions (Audit Commission 2008). PbR, foundation status and practice-based commissioning are leading to scrutiny of data on efficiency and to better data on outcomes (Dixon 2008). As there is a move to primary-care led purchasing, Darzi (2007) highlights the importance of developing services which are nearer to the patients' homes and the possible development of integrated care progressed through joint management of a budget by hospitals and practices in which cancer follow-up could be organised. As discussed previously, studies have shown that most recurrences are detected by the patients themselves or with imaging and not within the clinical setting. There is international concern about the large numbers of patients in breast clinics. The worry is that the demands of follow-up will limit the time available for patients with active disease (Grunfeld et al 1996).

Grunfeld, Fitzpatrick, Mant and Vessey (1995) aimed to determine the views of GPs and specialists in follow-up of patients with breast cancer in remission with a specialist emphasis on their views regarding the transfer of routine follow-up from the hospital to General Practice. The study did not ask the patients' views of follow-up but sent questionnaires to the specialist clinicians and organised interviews and questionnaires for the GPs. Of the 376 multi-clinical disciplines contacted by questionnaire 252 (77%) responded. The clinical oncologists and radiotherapists provided the majority of specialists and minorities were medical oncologists, surgeons or members of another

professional group. The questionnaires were sent to the eminent professional groups i.e. British Breast Group and the National coordinating Group for Surgeons on the National Breast Screening Programme. However, the response rate was poor from the surgeons so their views have not really been included.

Of the 226 GPs sampled, 220 were available to be interviewed and for varying reasons 180 completed interviews with a response rate of 81.8%. Grunfeld et al. (1995) found 45 (25%) of 180 GPs had less than 10 patients in their practice with breast cancer. 65 (36.1%) GPs had 11-50 patients with breast cancer. Few GPs (17; 9.4%) had ever held clinical posts in oncology or radiotherapy. The main aim of the study regarding GPs' and surgeons' views had not been met as the surgeons' views had been underrepresented. There could also have been a possible bias because some of the GPs may have been more interested in breast cancer. GPs were interviewed and sent a questionnaire, possibly providing more accurate information.

To implement a policy of GP follow-up, a number of practical points would need to be considered such as discharge letters and efficient access to the MDT if a problem arises. Further, GP follow-up could only work with the co-operation of the Primary Health Care Team. In relation to competency, skills to examine irradiated breasts, the psychological needs of patients with breast cancer and GPs' concerns about the increased workload and adequate compensation will need to be addressed.

The second study by Grunfeld et al (1996) sampled 296 women with breast cancer in remission undergoing hospital follow-up at two district general hospitals in England. Both hospitals service a mixed urban-industrial and rural population. The GPs' or specialists' views were not ascertained but the objective of the study was to assess the relationship of time of diagnosis to recurrence and the effect on quality of life when primary responsibility

for follow-up was transferred to the GP. However, the follow-up time was only eighteen months and only 26 women were diagnosed with recurrence. Eighteen of the twenty six women presented at intervals between appointments and half (7/16 or 44%) of the recurrence in the hospital group had presented to their GPs first. These women also knew they were involved within a research project and were not discharged from hospital follow-up which may have clouded their views (Rainsbury 1996).

In 2006 Grunfeld's group reported a Canadian multi-centre study involving 968 patients with early stage breast cancer, who had completed adjuvant treatments for breast cancer and were disease free at nine and fifteen months from diagnosis. Patients were randomly allocated follow-up in the cancer centre or follow-up from their family practitioner with annual mammography. Fifty four women, diagnosed with breast cancer recurrences (11.2%), were detected by the family practitioner group and 29 (6%) deaths were recorded. In the cancer centre group there were 64 recurrences (13.2%) and 30 deaths (6.2%). There was no difference in quality of life in either group. This indicates that patients can be offered breast cancer follow-up by family practitioners without concern that important recurrence-related serious clinical events will occur more frequently or have an effect on quality of life. This study and others has been reviewed by The National Cancer Research Group (NCRG) and other Primary Care Development Groups who agree that the level of clinical assessment, conducted in the privately funded Canadian system, was not achievable within the NHS and that a more flexible approach may be necessary (Donnelly, Hiller, Bowden, and Coleman 2007). Macleod et al. (2000) carried out an investigation to ascertain whether there was poorer survival between deprived women compared with affluent women and whether it is related to their NHS Care. The retrospective records from GPs and five hospital trust archives were reviewed of 821 women who had been diagnosed with breast cancer between 1992 and 1993 and lived in the most affluent and most deprived areas of one locality in Glasgow. The findings show



that access to care from the GP and acute oncology settings were similar. Admissions to hospital, with conditions unrelated to breast cancer, were more common within the deprived group and consultation in general practice was higher in the deprived group after the second year of diagnosis. The study concluded that affluent women did not receive better care than the deprived group but that women in the deprived group had more comorbidity that is associated with health inequalities in the socially deprived groups rather than a different level of clinical oncology or surgical cancer management. In this context general practice is uniquely placed to provide the necessary emotional support for patients from socially deprived groups and to be involved in the treatment compliance of adjuvant hormonal manipulation, bone health and trial follow-up (Donnelly et al. 2008). Hayes (2007) explains that effective primary local treatment combined with long term adjuvant therapies can both prevent recurrence and improve survival and therefore follow-up care needs to ensure long term compliance and GPs are in prime position to lead this component of the pathway.

Donnelly et al. (2001) investigated how women with recurrence presented to the outpatient department at their hospital in Humberside U.K. At this hospital 643 women presented between 1992 and 1998. From the 643 patients with operable breast cancer a complete set of data was available for 104 patients with recurrent disease. There were 67 metastatic patients and 37 with loco-regional recurrence. Seventy seven (74%) of patients were seen at an interval when they became symptomatic. Of the patients, whose recurrence was confirmed at a routine clinic, eighteen had symptoms. All cases of metastatic disease and 28/37 cases of loco-regional disease were symptomatic. Donnelly et al. (2001) discussion with GPs appears to be in line with Grunfeld et al. (1995) that with education and easy access back to the hospital this would enable community healthcare professionals to play a greater role in breast cancer follow-up without detriment to patient care.

Taking into account the results of all the studies cited previously, and the work presented in relation to the importance of including the people whom the service affects, Grunfeld et al. (1995) believes that community follow-up ensures continuity of care and support for the patients and is the ideal method of shared care. The specialist provides primary treatment and the general practitioner provides continuing care. The specialist becomes involved again if the disease recurs. In answer to the letter, Maher, Bradburn and Adewuyi-Dalton (1995) responds by raising the issue of the patient's views. Maher et al. (1995) describes a multicentre study of hospital follow-up versus follow-up based in the community. They sought patient's views, using research methods described by the College of Health. Focus groups of women in remission were drawn at random and from the network of cancer support groups. The patient's view challenges the utilitarian approach of clinicians and the purpose of follow-up being shared with primary care. The patients expressed their anger and distress about being discharged to their general practitioner for follow-up without having the support and specialist services of the hospital available in the community. Grunfeld et al. (1996) viewed the hospital, its diagnostic tests, specialist physicians and breast care nurse - as the patient's best defence against a recurrence of their cancer. Although there were aspects of the hospital systems they did not like, such as the waiting, the rushed consultations and the lack of continuity of care, - these were seen as the 'trade-off' for guarding against a relapse. For patients, an acceptable model of community based care would include clinics staffed by someone with specialized knowledge of cancer, for example a breast care nurse, - and a fast track route back to hospital care when this is required. This would overcome the perceived lack of knowledge of their special needs by general practitioners and provide continuity and a specialized intermediate service. Hospital specialists would also have a reduced workload, allowing them to concentrate their care on those who really need it.

### **3.2.6 Follow-up needs of patients**

Adewuyi-Dalton, Ziebland, Grunfeld and Hall (1998) investigated the experience of follow-up among 109 women with breast cancer. This study interviewed the women exploring their views of follow-up in the outpatient hospital setting. Continuity of care and unrushed consultation were considered to be important and access to cancer expertise, the availability of tests and specialists were valued features of hospital based follow-up and, with the analysis of the data, appeared to be important at the early stages of follow-up. There were concerns that discontinuity led to a lack of personal and case familiarity and communication difficulties. A preference for continuity of care suggests that GP follow-up would be preferred, but access to specialist services appears important at the end of active treatment and transfer to the follow-up stage.

Koinberg et al. (2004) performed a randomized longitudinal multi-centre study of three hospitals in Sweden. Two hundred and sixty four patients were contacted by an external secretary and consecutively selected with stage I or stage II disease (UICC TNM 1997). Questionnaires were sent to the patients six months after randomization and every six months thereafter over a three-year period, with a seventh questionnaire after five years. The medical notes were also reviewed in 2001 and if any ambiguity was found regarding a certain medical intervention, this meant the patient was excluded from analysis of that part of the study. One hundred and thirty five women were excluded as one centre had scheduled 135 women to see the surgeon or oncologist and one woman developed recurrence before the randomisation and had to be excluded. Finally the analysis was on 131 patients to see the surgeon/oncologist and 133 to see the nurse. The study showed that a nurse based follow-up system with check-ups on demand was similar to physician follow-up. Overall satisfaction at the end of each year with access to service and telephone was 93% to 100%. The study was not set up to explore differences in survival, but found no indication that safety was endangered by a nurse-led system of follow-up.

Renton, Twelves and Yuille (2002) surveyed opinions of patients within routine follow-up to assess their current satisfaction and establish the issues, which they viewed as important. A self-completion questionnaire was used to ascertain the views of 134 women who had received treatment for breast cancer in an acute hospital in Glasgow. Again the risk of recurrence and effects of treatment were considered the most important topics for discussion for 113 (84%) of the women and 89 (66%) patients felt it was important to see the same member of staff at each visit. Eighty six (64%) would have been satisfied with a nurse led system of follow-up whereas only 51 (38%) would have been happy to see the GP.

Gulliford, Opomu, Wilson, Hanham and Epstein (1997) compared experiences of women within standard follow-up with those who had reduced follow-up at the time of mammogram (annually) in a London hospital. One hundred and ninety six out of two hundred and eleven women were randomized to less frequent follow-up. Women under fifty years of age and with aggressive disease did not participate in the study because of their differing follow-up needs specific to their clinical situation. All patients participating in the trial were given telephone access to report if they were concerned about a new symptom. Gulliford et al. (1997) established that a minimum of four hours 'door to door' was required for clinic attendance in 73 (35%) patients. Thirty seven patients needed to take time off work and 80 (38%) patients were accompanied by another person of whom 20 (25%) needed to take time off work. Sixty seven (32%) incurred no personal costs in attending clinic, while 49 (23%) of the remainder incurred costs in excess of £10.00 and for eight (4%) the cost was more than £50.00. This study was in 1997. The expense incurred by patients attending hospital appointments has now increased. It appears from this study that less frequent follow-up may be acceptable.

### **3.3 THE DEVELOPING ROLE OF NURSES.**

The publication in 2004 of the Nursing and Midwifery Council (NMC) document *The NMC Code of Professional Conduct: Standards for Conduct, Performance and Ethics* has allowed nurses to consider extending their roles formally in order to enhance the holistic approach to patient care. The document states that the nurse must be satisfied that each aspect of practice is directed to meeting and serving the interest of the patient. It also states that the nurse must ensure that any adjustment to the scope of his or her personal practice must be accompanied by an acknowledgement of his or her personal limits in knowledge and skills.

#### **3.3.1 Role boundaries – medical and nursing overlap**

MacAlister and Chiam (1995) argues that, in the past, allied healthcare professionals delegated to nurses tasks they found inconvenient or boring. Shepherd (1993) suggests that the undertaking of medical tasks enhances the professional status of nurses, a view which could be understood as seeming to demean the nursing profession as a whole (Porrett 1996). Gee (1995) highlights the argument that anyone with manual dexterity and a degree of comprehension could be taught to perform certain medical tasks. However, it is not the action of the medical task but the responsibility and accountability associated with the task. Errors made by nurses who extend their practice will be judged by the standards of practice of a reasonable doctor and therefore their competencies are measured within a framework which is nurse owned to determine their skills where the main focus is to enhance patient care and maintain the therapeutic relationship of nurses and their patients (Gee 1995). The interface between nursing and medicine in specialist practice should include psychosocial assessment and intervention with patient teaching, counselling, health education, caring and comfort (Dressler 1994 cited in Gawlinski and Kern 1994, p183-190).

### **3.3.2 The emergence of Nurse Practitioners**

The need to develop cancer services to support patients in treatment and survivors of cancer has been reinforced by government policy in the United Kingdom. The National Cancer Plan (DOH 2000) redesigned care to ensure that patients and their families had timely access to treatment. NICE (2004) specifies greater detail in timely follow-up for cancer patients and their families. The Nursing Contribution to Cancer Care (DOH 2000b) sets out a strategic programme for cancer to improve information during and after treatment and more recently 'Action for London' (2007) discusses the diverse needs of patients in London with cancer and an educated workforce to meet their needs. This is also in line with the changing demographics and health inequalities discussed in The Cancer Reform Strategy (DOH 2007 and Darzi 2007). These changes in the population and policy have been major influences on the expansion of nursing roles and responsibilities. Recent reforms specify much greater pressure on NHS Trusts to provide high quality services to tackle cancer and improve the patient pathway. Therefore, specialist nurses are in prime position to understand the issues surrounding the extension of nursing roles and are made aware of all the implications of the NHS reforms to take control of the situation and, as Castledine (1996) requests, to bring coherence to a potentially fragmented healthcare system. Lemp (1995) takes the view that the emergence of a nurse practitioner should not mean that the nurses replace doctors, but that they are able to provide to the public a better quality and wider choice of services. As Pennery et al. (2000) point out in breast cancer follow-up, their research was not to prove supremacy in quality of care between the professions but evidence based discovery of the subtle differences between what doctors and nurses offer and the best professional service to enhance the patient experience in breast cancer follow-up. The concept of devolving aspects of care to nurses is not new. Midwives function effectively with a large degree of autonomy in a significant proportion of normal deliveries.

James, Guerro and Brada (1994) in Sutton piloted a nurse-led follow-up for new patients with central nervous system tumours during radiotherapy treatment. These patients are often disabled during radiotherapy and the majority have a poor prognosis, and all require clinical consultations dealing with issues of treatment, rehabilitation, care and support. It was a short audit over only eight weeks of the care of eighteen highly dependent patients. The transfer of care from conventional outpatient clinic to a nurse 'on treatment clinic' and the use of 'telephone clinic' decreased the patient work load. Unfortunately the authors cannot confidently claim that some patients may have wanted to see the doctor as the efficacy of the clinic was measured by its effect on work load, compliance and questions posed by the nurse herself, which may have caused bias. However, the authors report that the patients appeared satisfied with the nurse specialist clinic and that there was a 30% reduction in the medical outpatient work load. The implementation of the 'telephone clinics' offers an effective alternative to conventional outpatient clinics and is more convenient for patients.

Hammond, Chase and Hogbin (1995) described a nurse practitioner service that they had developed within The Royal Sussex County Hospital. In the breast clinic a nurse practitioner assessed new patients with non-worrying symptoms such as breast pain and she triaged referral letters from GPs. The research project was undertaken over a five-month period and its aim was to assess the effectiveness of a nurse practitioner as compared with that of two senior house officers, one male and one female. Following the patients' consent they were given several questionnaires including the Medical Interview Satisfaction Scale (Wolf, Putnam, James and Stiles 1978). The patients who saw the nurse practitioner expressed higher satisfaction than those who saw the male or female house officer. Where the possibility of cancer was present, the patients who consulted the nurse practitioner were less anxious than those who saw either of the two house officers. The article did not document the statistical values or numbers of patients interviewed. It is

difficult to review the results objectively but even with this small scale study in the 1990s nurse led interventions within breast care were being developed.

Earnshaw and Stephenson (1997) evaluated nurse-led follow-up clinics for breast patients. There were 191 clinic visits for breast cancer. Twenty four were for pre-operative counselling and 167 for follow-up. From the paper it is difficult to ascertain whether follow-up was meant to be within medical guidelines, once treatment had finished, or that the nurse would give interim follow-up support similar to the pre-operative information and support provided. In the course of the discussion the authors highlight the benefits of nurse-led care in continuity for patients and in longer appointments than those in general clinics. However, the opinions of the patients have not been ascertained and statistical analysis has not been provided. It is agreed by the authors that nurse-led clinics are cost effective and a clinically acceptable way of conducting breast cancer follow-up but that this is very hard to prove without formal scientific comparison.

### **3.3.3 Patient satisfaction with nurse-led services**

Garvican, Grimsey, Littlejohns, Lowndes and Sacks (1998) describe a study that assesses patient satisfaction with a nurse-led clinic and screening for breast disease in London and evaluates the clinical expertise of the nurses. The nurses distributed a specifically designed patient satisfaction questionnaire to 150 consecutive new referrals during a six-week period. One hundred and nineteen questionnaires were returned after a postal reminder - a response rate of 79%. A Likert scale was used to rank satisfaction. Forty seven (40%) out of 117 women responding to this question were satisfied with the amount of time they spent waiting at the hospital and 30 (35%) out of 113 women responding were satisfied with the facilities in the clinic. Only five women had expected to see a nurse. All women were satisfied or very satisfied with the clinical care received, and 19 (16%) out of 118 added specific praise to their responses. Overall, data showed that the patients were



significantly more satisfied with the nurses ( $p<0.0001$ ) than with other aspects of hospital care. Postal questionnaires were also sent to GPs. One hundred and two out of 150 (68%) were returned. Ninety nine questionnaires were analysed but only 91 were included for unspecified reasons. Sixty four out of ninety one (70%) GPs were aware of the role of the nurse but only 8/91 (7%) had informed their patients that nurses ran the clinic. Again this aspect of nurse-led care in assessing new patients is different from that of nurse-led cancer follow-up but, even so, nurses were acceptable to patients and general practitioners. The nurses' clinical skills compared favourably with that of other clinicians except for a lower percentage of inadequate samples which were aspirated by the specialist nurses compared with the rest of the team.

Faithfull, Corner, Meyer, Huddart and Dearnaley (2001) advocate specialist nurses as an important and cost effective resource in the care of men with prostate or bladder cancer. They compared nurse-led care in relation to the physical and emotional impact of treatment with conventional care. The study sample was of men who were prescribed radical radiotherapy ( $>60$  Gy). The men completed a self-assessment questionnaire for symptoms and quality of life during the first week of treatment and at weeks three, six and twelve. One hundred and fifteen of 132 gentlemen agreed to enter the randomized trial. Six (4%) refused and 11 (8%) were missed for inclusion in the study. Results indicated that, although the nurse was unable to influence the extent of the side effects from treatment or improve quality of life, the nurse-led intervention was effective in managing symptoms. Satisfaction with the nurse-led service was greater than with conventional care ( $p<0.002$ ) and costs were cut by half. However, in this study the views of the patients were not discussed.

Cox et al. (2006) investigated patient preferences in relation to follow-up after treatment for lung cancer and sought to assess the nurse-led option. Over a 34-week period 72 patients

who were deemed to be eligible for nurse-led follow-up attended 487 follow-up appointments. The inclusion criteria were patients with small cell or non-small cell lung cancer receiving follow-up care. Patients who were in other research trials or required urgent medical attention were not included. Sixty patients were approached and 54 (90%) agreed to participate. A questionnaire and vignette of different scenarios were used (nurse led, telephone, GP or standard follow-up). Thirty four out of fifty four (63%) of eligible patients completed the forms, as did 10/20 carers (50%), 20/31 (65%) of staff and 11/38 (29%) of GPs. Following the weekly lung MDT meetings, patients indicated whether they were interested in taking part in the project. The research team explained the project further and gained consent. At the same time the researcher asked the patient to nominate a family member to whom the questionnaire could be given. Likert scales were used to rate acceptance of scenarios. The patients were happier to see the doctor ( $p=0.18$ ) than to see the nurse but happier to see the nurse than to see the GP ( $p=0.12$ ). All groups were satisfied with nurse-led follow-up if there was medical backup and if the nurse was empowered to refer the patient onwards, if needed. Again most useful about the visit was the reassurance given, adequate treatment if necessary, update in condition and relevant advice and information.

Corner et al (2002), at the Royal Marsden London, entered 203 lung cancer patients to a randomized control trial to validate the acceptability of nurse led follow-up. These patients had completed their initial treatment and were expected to survive for three months or more. The acceptability of nurse-led follow-up was high and there was no significant difference between the groups in their overall satisfaction. There was no difference in survival between the nurse-led and the conventional medical-led service. However, the nurse recorded progression of symptoms sooner than the doctors ( $p=0.01$ ). But the potential for bias must be recognized. There were differences in the co-morbidity between the two groups, which were not fully addressed in the discussion. The differences were

mainly in cardiac disease where the nurse group had 29 patients and the doctor group had four. The nurse group also had 28 patients with gastrointestinal disease while the doctor group had 20. The randomisation was not fully described in the paper and as there were more patients with co-morbidity in the nurse-led group than in the controls, earlier detection of symptoms would occur as disease progressed rather than by a difference in the quality of care provided (Mongelli 2002). Furthermore, the paper describes 100 patients within the nurse-led group and 103 in the conventional group of medical follow-up. One patient was excluded which meant the total was 202 patients. The patients in the nurse led group had access to two Clinical Nurse Specialists without appointment and telephone contacts which were three per month for a mean of three minutes. Rodger (2002) advises caution on the grounds that the study compares open and frequent access as against infrequent hurried consultation with a different registrar at every visit.

McCaughan and Sorley (2007) explored the healthcare needs of women attending a consultant-led breast cancer review clinic and the healthcare professionals' perceptions of ways in which the service could be delivered more efficiently and more effectively. A qualitative design was adopted, using observation during seven outpatient oncology and surgical breast clinics. Interviews were carried out with a convenience sample of twenty one women, three breast care nurses, four oncologists, three surgeons and an out-patient sister. Although the women saw themselves as returned to a pre-cancer state they still had fears of recurrence and a need for reassurance. Although this need was met during the clinic visit, they identified many psychosocial needs as not having been met. It could be argued that nurses seemed to be underused as a potential source of support for patients in the follow-up setting. Medical and nursing staff recognised that the women condition is needed to be reviewed but acknowledged that appropriately prepared nurses could deliver a more holistic and efficient service.

### **3.4 PEER SUPPORT**

An important avenue of support for women who have been diagnosed with breast cancer, is through self-help groups and support groups and the difference between these needs to be acknowledged. Support groups are defined as groups that exchange information and are led by a trained facilitator. Support groups are different from self-help groups, which do not have an expert leader (Helgeson, Cohen, Schulz and Yasko 2000).

#### **3.4.1 The benefits of peer support**

Much has been written regarding who benefits from support and educational intervention. Helgeson et al. (2000) found that a subgroup of women benefited from the peer-discussion group - those who lacked emotional support from their partners or who, conversely, reported more negative interactions with their partners. In general, peer-support groups are thought to be beneficial because they compensate for deficits in the patient's naturally occurring social network. Campbell, MacLeod and Weller (2002) explored the benefits of an exercise group and the experiences of women undergoing breast cancer treatment. The group helped to reduce barriers to physical activity, such as difficulties in prioritising exercise over caring roles and worries about changed appearance. The women valued being with other women who were in a position similar to theirs and developed friendships from these meetings. Interestingly some respondents felt that the 'last thing' they wished to do was to talk about cancer. Therefore these results challenge stereotypes about women invariably preferring to cope with cancer through emotional disclosure. However, there is not universal agreement that self help groups are an effective support mechanism, Helgeson et al. (2000) suggest that when patients, who are happy with their social support, attend self-help groups, their level of satisfaction can change and the group can cause harm. The reason for this may be that, as women discuss with others, they then re-

evaluate their own experiences and social networks. Such discussions may have the potential to lead to negative interactions (Helgeson et al. 2000). It is disturbing to think that patients could be harmed by these interventions and there may not be as clear a solution, therefore, to follow-up as some clinicians may have believed. Patients' social network would need to be assessed and they should not be forced to join support groups if they are happy with their own social network.

### **3.4.2 Alternatives to group meetings**

Practical difficulties involved in group meetings have been identified, such as tiredness, distance and cost and strategies, such as the use of telephone support groups, have been developed to help circumnavigate some of these difficulties (Chamberlain - Wilmoth, Tulman, Coleman, Stewart and Samarel 2006). Positive findings from studies with HIV patients and families, AIDS patients, and the physically disabled elderly reported outcomes of decreased isolation, improved coping, and better mood (Weiner, Dupont-Spence, Davidson and Fair 1993). Chamberlain et al. (2006) describe their study in which women received educational materials and telephone support from oncology nurses and another group received educational material alone. Participants who received telephone support for one year, in addition to educational materials, reported improvement in their attitudes toward their breast cancer and better relationships with their partners. This adds to the body of evidence that telephone support is an effective alternative to support groups and may be appropriate for those with limited access to such groups because of distance, work demands, or family situations. Sardell, Sharpe, Ashley, Guerro and Brada (2000) also identified the telephone as an efficient way to provide follow-up. It allows for a large number of people to be assessed; it is convenient; it allows for immediate response and the length of time can be controlled (Cox and Wilson 2003). In relation to breast cancer follow-up it could enable the early identification of problems such as recurrence,

psychological difficulties and side effects of adjuvant treatments, before they become critical, and allow patients to be directed to the most suitable resources – organising tests and bringing the patient back for the results (Keeling et al. 1995). Furthermore, direct telephone access to patients ensures they are quickly brought back into the system, if and when necessary (Koinberg et al. 2004).

Use of computer-based online services that provide access through the Internet, which includes the World Wide Web (www.), may be the most widely applicable and beneficial computer application with regard to breast cancer follow-up. Weinert, Cudney and Winters (2005) developed a 'women to women' project to help chronically ill rural women adapt to long term chronic illness by providing support via the computer, with nurses monitoring the usage and providing the I.T. training for patients. Obviously, this was expensive and time consuming within a rural area but the use of breast cancer care and computer chat rooms may be a way forward to provide information and support to women with breast cancer and could be incorporated into a survivorship programme supported by the MDT (Haylock, Mitchell, Cox, Temple and Curtiss 2007). Connecting patients with peer support e.g., individuals, groups, or the DIPEx breast cancer module, an internet resource based on illness narrative interviews, may help them to recognize that they are not alone in their experiences and to identify new ways of living with breast cancer (Kelly 2004) (<http://www.dipex.org>). However, in the current financial climate and reduction of specialist nursing staff there is a struggle to implement supportive care in competition with meeting cancer targets. Therefore to meet the supportive needs of cancer patients the MDT needs to be resourced for better organisational support and the ability to monitor achievements (Willard et al. 2005).

The recent Cancer Reform Strategy (DOH 2007) recognises the challenges in shifting cancer care from the inpatient to the outpatient setting. There is also a drive to work more closely with cancer charities to provide support (DOH 2007). However, against the background of financial pressures on many NHS trusts, specialist nurse posts have increasingly come under threat as finance directors of primary care and acute trusts search for ways to reduce their deficits (Dinsdale and Waters 2006). Mike Richards, the cancer 'Tsar', made the suggestion that the largest single expenditure on cancer is not new drugs but in-patient stay. He continued by highlighting that the UK kept patients with cancer in hospital longer than other European countries (Hitchin 2007). It could be argued that there is a need for innovational practice to discharge patients earlier and to work closely with community colleagues and in line with the cancer reforms (DOH 2007) and Darzi (2007).

### **3.5. GOVERNMENT POLICY IN SUPPORTIVE CARE.**

#### **3.5.1. Supportive and Palliative Care Guidelines.**

The Cancer Plan (2000) emphasises the importance of supportive care but does not clarify the nature and content of supportive interventions (Skilbeck and Payne 2003). However, the new N.I.C.E. supportive and palliative care guidelines states that supportive care should be from pre-diagnosis through the process of diagnosis and treatment, proposing that supportive care is given equal priority alongside diagnosis and treatment. However, in practice it appears that it is the treatment agenda that shapes the organization of services. Recent policy initiatives to reduce waiting times have placed heavy demands on outpatient clinics. However, this expansion in capacity has not been matched by an increase in resources (Willard et al. 2005). Therefore out patient staff prioritise the moving of patients through the system as quickly as possible and therefore restrict patient

consultations to treatment related issues, thus creating the potential for compromising patient support (Willard et al. 2005). If a Clinical Nurse Specialist's (CNS) efforts to give supportive care are successful, the ability to record the intervention could be constrained by ensuring that informed consent to treatment is within the cancer target waiting times. Many CNSs do not have clerical staff and therefore do not use Dictaphone to capture the intervention accurately but handwrite nursing notes at a later date. Therefore the issues of time accommodation and lack of administration staff does not lend itself to supportive care.

Further constraints on the CNS to provide supportive care is the reduction in junior doctor hours and insufficient medical staff to provide care (DOH 2002). In particular the CNS is vulnerable to the demands of role expansion and doctor substitution with the focus on treatment-related issues rather than on the person experiencing the disease (Willard et al.). The appointment of MDT teams does not allow for clarification of supportive needs or address Trust issues around how support can be delivered but is dominated by a medical staff desire to attend to patients' treatment needs, thus shaping the role of the CNS.

### **3.5.2. Survivorship in Government policy.**

The concept of user involvement is a key NHS policy driver, promoted to encourage patients to exert greater control over their health care and improve services (Health and Social Care Act 2001). The views of users has centred on the application of their experience to develop services and materials to deliver peer support, patient information and staff training (Fudge, Wolfe and McKevitt 2008). From existing literature the fear of cancer recurrence appears to be the most distressing and can be disabling to the patient and families (Okamura et al 2005). The central issue in cancer recurrence seems to be the loss of hope and from the literature it appears that the driving force for women wishing to attend clinic appointments is for the reassurance that they remain well. The Cancer Reform Strategy (DOH 2007) has included follow-up as part of its vision. It discusses a



cancer survivorship strategy but at present does not give clear guidelines on how this may develop and to date has not involved users. NICE guidelines (2002) recommend reducing follow-up appointments but also have not sought the views of the users and those key poignant issues concerning the 'loss of hope' and incongruent with the 'user involvement' element of Government policy. As women with breast cancer are living longer, care needs to focus on survivorship and on issues related to the quality of life so that women may recover from breast cancer and move from illness into wellness (Revenson and Pranikoff 2005). The side effects of treatment, the changes in body image, the fear of cancer recurrence and possible death are enormous issues to come to terms with and resolve (Yeo et al. 2004). The loneliness for women to deal with and the fear once treatment has completed requires support in a structured and equitable manner (McKinley 2000). The partner or family members will have to provide practical and emotional assistance which can cause additional stress (Bultz, Secca, Brasher, Geggie and Page 2000) and will need discussions in the follow-up setting. Currently, in key cancer policy documents, these imperative issues have not been referred to or direction given on 'how' the MDT or clinicians in primary care can address these sensitive and psychosocial elements to support. In the follow-up stage the meaning of 'recovery back to health' is an important concept of to care. The meaning of health is complex and means different things different people and professions and therefore there are different objectives to be met by the different patients and professionals. However, there has been little penetration of this in relation to daily health care provision or on behaviour or lifestyle change for patients, and is not seen to be incorporated into care (Raphael and Bryant 2002).

### 3.6 SUMMARY

Breast cancer continues to be a major public health challenge. The literature indicates follow-up visits to hospital out-patient clinics for as many as 10 years after diagnosis and includes history taking, physical examination, blood tests, imaging and mammography, (Tomiak et al 1993). There has been much controversy surrounding this practice, (Schapira et al. 1991, Wertheimer 1991, Dixon 2008). In relation to survival benefit and follow-up, Van der Sanger et al. (2006) and Montgomery et al. (2007) discussed a lower ten year survival for whom recurrence was detected clinically, as compared with image or patient detection. However, after fifteen to twenty years from diagnosis there were no differences in survival.

Survival has improved since the 1990s and 1980s but as Jones (2005) highlights, cancer has not changed but diagnosing and treatments have changed to reduce relapse and death. Unfortunately, the predicted improvement in long-term survival for women aged 15-49 at diagnosis is much smaller than that of women aged 50-69 years. These young women have many differing needs that will impact on follow-up services. Most recurrences are detected by patients themselves who frequently present at unscheduled visits in the intervals between follow-up appointments, (Churn et al. 2001, Grunfeld 2006, Montgomery et al. 2007b) and since 2000 more recurrences have been detected on mammogram (Van der Sanger et al. 2006 and Montgomery et al. 2007a). N.I.C.E. (2002) published guidelines do not support long term follow-up for any patients of any age and encourage cancer networks to develop local guidelines. ASCO recommend a survivorship programme which has been developed from twenty years of work. Local user groups in the UK and the Cancer Reform Strategy (2007) have decided to develop a similar programme.

Alternatives to hospital out-patient clinics have been proposed, (James et al. 1995). In

countries with a strong primary care base, one alternative is to give responsibility for routine follow-up to the General Practitioner, with the option to re-initiate specialist hospital care if problems develop. General Practitioners have shown an interest and a willingness to undertake this responsibility, (Grunfeld et al 1995, Grunfeld et al 1996, Grunfeld et al. 2006). Nevertheless there are issues of competency due to patient numbers, adequate knowledge and skills within the specialty. Evidently, there was benefit from community breast cancer follow-up for the patients. In particular people found they did not have to take so much time from work. It was easier to travel to and less of a financial burden. In contrast to this account Maher et al. (1995) explains that there were aspects of hospital follow-up in which they found difficulty but the hospital was seen as having skill in cancer management and as understanding the magnitude of a cancer patient's life. The authors suggest a model of community care which would include clinics staffed by someone with specialised knowledge of cancer, - for example the breast care nurse, - and a fast track route back into the hospital if this was required. This would overcome the perceived lack of knowledge of these patients' special needs by the G.P. and provide continuity and a specialised intermediate service. This proposal would also coincide with the Cancer Reform Strategy (2007) which promotes swift advice and treatments at local surgeries and health centres but it also promotes prompt access to specialist hospitals with a fast and seamless episode of specialist hospital care.

This very innovative idea involves several important issues. The literature looks at the developing role of the nurse. There are many discussions around improving quality of care for local people ensuring efficient and effective care. Developing the role of the nurse into that of nurse practitioner may assist in providing this high class service. There is nothing new in nurses cutting waiting times (Paniagua 1997). Furthermore, many are concerned about the cost to nursing. If nurses extend their role, who will do the 'caring'? Government documents such as The Calman Hine Report (DOH 1995) and the reduction

in junior doctors' hours (NHS Management Executive 1992) may have accelerated these nurse role developments. As Porrett (1996) explains, if nurses are not part of the management chain, then changes to nursing will be forced upon the profession without consultation.

Hospital Trusts have reduced junior doctors' hours in line with the European directives and are advancing nursing practice and patient care and these developments appear to score highly in patient satisfaction questionnaires (Hammond et al. 1995, Garvican et al. 1998, Cox et al. 2006). However, developing the first will not necessarily achieve the objectives of the second, especially if it is medically defined and driven, and despite the introduction of the title "Nurse Practitioner".

Support groups and self-help groups provide positive and negative aspects of care for breast cancer patients. In particular, the patients can begin to re-evaluate their coping skills and perhaps compare their different experiences which can be positive and negative (Helgeson et al. 2000). It is suggested that educational groups provide additional information alongside telephone support (Cox et al. 2003), (Koinberg et al. 2004).

There is an abundance of retrospective audits and reviews but there is a need for a randomised control trial since proposals regarding follow-up and NICE (2002) guidelines are not evidence based. A trial of hospital based specialist follow-up versus alternatives is required. In this trial alternative to follow-up could be promoted that meet the patients' needs and audit clinical practice (Donnelly et al. 2008). Kimman et al (2007) in the MaCare Trial compare the cost effectiveness of four follow-up strategies for breast cancer patients in follow-up. This random control trial will investigate the cost and effectiveness of these strategies. Donnelly et al. (2008) proposes the iBreast Trial which includes several alternatives to meet the needs of the patients.

The effect of a breast cancer diagnosis changes a woman's life for ever. A woman needs to draw on many resources internally and externally to survive and recover. Once treatment has ended, women can feel alone without the clinical team and require continuation of medication. Follow-up needs to incorporate a clinical aspect and a supportive role. The extensive literature addresses the complex issues of cancer diagnosis and the needs of women in follow-up. There appears to be paucity in the literature where the views of the women are central and these views are then teased out through the MDT and GPs, this is what this small study will investigate. Grunfeld et al. (1995), Grunfeld et al. (1996) and Grunfeld et al (2006) indicate that follow-up care can be practised in the community. No study has investigated GPs who could not be involved in follow-up and what are the barriers that would prevent them, no study has asked the MDT, in conjunction with the women, their views on breast cancer follow-up. The concept of user involvement is to encourage patients to have greater control over their health care and improve services but needs the evidence from the women, primarily, and the key stakeholders. With these views feeding into one another a new model of breast cancer follow-up could be developed locally as the impact of breast cancer does not stop once treatment has finished. This is poignantly described by McKinley below.

*“Being in the midst of active treatment means being seen regularly by a nurse or a physician – being cared for. As I got up from the radiation table for the last time and walked away, I found myself alone with a cancer ghost who would not let me forget where I had been or allow me to freely choose where I might be going.”*

(McKinley 2000 p.479).

## **CHAPTER FOUR**

### **METHODOLOGY AND METHODS**

#### **4.0 INTRODUCTION**

The primacy of the stakeholders' views was the driving force behind the development of the research design. The primary aim of the study was to determine whether breast cancer follow-up clinics meets the needs of the women who use the service, and the purpose of the study was to inform the development of a new model of breast cancer follow-up. The literature currently debates the value of breast cancer follow-up in relation to the investigations used clinically to detect local or regional recurrence (Dixon and Montgomery 2008). Other studies have described the impact of the diagnosis of breast cancer on women and their families in relation to their quality of life and psychosocial aspects to rehabilitation (Revenson and Pranikoff 2005). Finally other researchers have investigated the role of primary care in follow-up management (Grunfeld 1995). Therefore this research needed to incorporate all those views as a group to develop a service locally and uniquely. The research approach needed to ensure that the views of the patients, the GPs, the key clinicians, based in the NHS trust, were heard. However, the voice of the women needed to be the primary focus of the research. The issues emerging, following a diagnosis of cancer, are complex and in order for the data to capture this information the methods used in the research design needed to be underpinned by a theoretical framework that will discussed below.

To gain breadth and depth of understanding of the issues surrounding the diagnosis of cancer and its impact on women and the service providers, it is important that their views are documented in both numbers and words. Quantitative and qualitative dimensions of life are not exclusive of each other and therefore combined research methods were

needed to gain an understanding of the totality of the patient experience (Yoshikawa, Weisner, Kalil and Way 2008).

#### **4.1 THEORETICAL FRAMEWORK TO UNDERPIN THE METHODOLOGY.**

To develop the breast cancer follow-up services locally the early involvement of the women who use the service was a key component. Involving them at the earliest stage in the research process led me to understand from a users' perspective the service provided and its relevance in meeting their needs following the diagnosis of cancer and its treatment. I wanted to identify the key aspects of care for the users locally and whether these areas were being met by the follow-up services provided (Vivar, Canga, Canga and Arantzamendi 2009). A focus group identified the patient perspective and GP interviews gave a community viewpoint. This enabled the development of the GP and patient questionnaires and themes for the MDT interviews. This would assist with a new model of care built on the views of all the stakeholders and the current gaps in the literature.

The methodology used in the study needed to capture these important elements of follow-up for the women using the service. Therefore to represent the views of the women who use the service and make these views central to the research a combined methodology was used to ensure the issues discussed in the focus group were asked of the women in the outpatient setting. This meant that the questionnaires were designed by the people who use the service rather than standard tools and richer data collected to be used locally to develop the breast service.

The research design needed to gain these views from the MDT in the study and any other important aspects of breast cancer follow-up. The key informant interviews with the GPs set the scene for the GP questionnaires and the MDT interviews gave the views of the

clinicians from the acute NHS trust. This would provide the views of all the stakeholders but the women who were diagnosed with breast cancer were central to the research and able to inform a new model of care. The design for this study needed to capture this data and highlight aspects of care that may not be met in the current follow-up service. The focus group and interviews generated the qualitative themes of care and the questionnaires quantified if there was a problem perceived by patients, with care delivery in the breast cancer follow-up clinics.

In conclusion the key issues to inform the development of a new service for breast cancer follow-up needs to have not only the key clinical stakeholders involved but must recognise the primary stakeholders as the patients – the women's views – are paramount. The other service users - The MDT and the GPs are aware of this multifaceted approach to care but the women's voice does not appear to be heard in current policy development. This is highlighted especially in the latest Cancer Reform strategy when plans are to develop user involvement but make a radical change to practice without asking the patient's views.

## **4.2 THE AIM AND PURPOSE OF THE STUDY**

The primary aim of the study was to determine whether breast cancer follow-up services meet the needs of the women who use the service, and the purpose of the study was to inform the development of a new model of breast cancer follow-up.

## **4.3 THE RESEARCH QUESTIONS**

The primary questions that this study set out to answer were:

1. Do women feel breast cancer follow-up services meet their needs?
2. What do GPs perceive the purpose of breast cancer follow up to be?
3. What do the MDT perceive as the purpose of breast cancer follow-up to be?



#### **4.3.1 The study objectives**

The key objectives of the study were to:

1. Develop tools for collecting the views of patients and GPs
2. To identify the views of patients, GPs and hospital clinicians on the existing breast cancer follow-up service.
3. To explore alternative strategies for delivering an improved breast cancer follow-up service.
4. To develop proposals for a new model of breast cancer follow-up service.

#### **4.4 THE STUDY APPROACH AND DESIGN**

##### **4.4.1 The research approach**

This study investigates real life situations of people involved in cancer and its management. To gain breadth and depth in relation to the different aspects of a breast cancer diagnosis and follow-up a combined approach has been adopted using both quantitative and qualitative research methods. Morrow and Smith (cited in Brown and Lent, 2000 p199-230) specify three areas where qualitative methods diverge from quantitative: focus of inquiry, research setting and the role of researcher. These differing areas are vital in capturing the rich data of the human experience of breast cancer to inform and make sense of the numerical data.

In qualitative research, the focus of inquiry is on a rich and complex exploration of the experiences of a small number of individuals. Qualitative research tends to emphasize the dynamic and individual aspects of the human experience (Silverman 2000). Morrow and Smith (cited in Brown and Lent 2000) describe the goal of qualitative research as gaining a

deep understanding of one or more people who are unique. In qualitative research the setting is extremely important as it provides context and determines how the individual behaves. Therefore in this study I spent time in the individual's environment to reach an understanding of their experience and to help the individual to explain the meaning of this. This was paramount to the research as the views of the women were central to the development of a new model of care (Morrow and Smith cited in Brown and Lent 2000).

The quantitative approach gave the numerical data to quantify the importance of the themes from the focus group and key informant interviews. This data highlighted the key components of a new model of care and uniquely to this study what the barriers or resources needed to make a change to meet the needs locally.

Combining the qualitative and quantitative methods allowed the limitation of each model to be transcended by comparing findings from the differing perspectives. This promoted rigour as the decisions I made about the themes generated had to be discussed openly. I conducted the interviews and focus groups and therefore it was my interpretations of the data collected. The quantitative approach used, allowed for a more complete, wider picture to emerge and this increased the study's validity (Williamson 2005). For example the focus group discussions highlighted many difficulties with breast cancer follow-up as it is currently delivered. The patient questionnaire did find some patients were happy with the service. This does not indicate that one method is better than another in seeking the truth. Combining methods creates a deeper understanding and contradictions to be explored.

#### **4.4.2 Involving users in research**

In the UK the Department of health has strengthened its policy of involving users in research (DOH 2006b) with current research strategy stating that patients and the public must be involved in all stages of the research process (DOH 2006b). There are increasing number of research projects in which users are involved all stages of the research process from research design, participating and disseminating research findings (Trivedi and Wykes 2002). For this research project the women were research participants only and not part of a research team. Ethically there were conflicting issues locally which would have caused difficulty in participating in an action research project. Involving the women early in the research process assisted with the research design. There was no guarantee that the literature, and the experience of the women in this study would be the same. However, the themes from the focus group coincided with the literature and exposed new and exciting areas for investigation. The experience of the women in the focus group and the findings from the questionnaires meant that, even though some of their discussions were painful, it was a way of achieving positive outcomes from changing clinical practice. The focus group was used as a vehicle to express their concerns in a way that the participants would not have had the chance to do before.

Ross et al. (2005) notes a very positive way in which the users reported their involvement in personal benefit and the input they gave to her study. This was true of the focus group in this research they found it therapeutic to discuss their feelings. However, due to cancer policy and some local strategic development it would have been difficult for them to contribute to local developments. Work by Ross et al. (2005) regarding slips, trips and falls had engagement from the PCT to make change to practice. In this study the research would inform the changes to the service and then with policy and local strategy develop those changes. It is increasing difficult to engage service users in areas of research unless they contribute directly to local development as with Ross et al. (2005). There was benefit to the research for all the stakeholders regarding slips, trips and falls. However,

with the development of cancer follow-up the key areas of importance were different for the service and the users and therefore full engagement to implement change would have been difficult.

In the literature there is much written about the positive experience of user involvement. It is unclear whether this signifies that such involvement is always positive or if negative experiences are not reported as frequently (Caldwell, Coleman and Holmshaw 2008). As stated before the relationship between the person diagnosed with breast cancer and the clinical team is complex and as Caldwell et al. (2008) discuss when individuals from different backgrounds and experiences come together there is a risk of unequal distribution of power. Reed, Weiner and Cook (2004) stress that researchers need to question both their motivations for user involvement in research and whether the involvement would be empowering or exploitative to the users. In trying to inform the different strands of the research in this project there would be inequitable distribution of power between patient and doctor. The clinician remains to have the power to treat the patient and therefore the patient may not be able to express how they really feel regarding their experiences along the patient pathway. This had potential to frustrate the aim of the study and exploit the patient doctor relationship. To ensure that this did not happen in this piece of research each group or discipline were interviewed separately. Therefore all stakeholders were listened to but one discipline did not dominate another.

Finally, to engage the users in the research project would have involved time and education. This would have resource (financial and time) implications that would have been difficult to estimate. In addition the users should be paid and have all their expenses met in accordance with the principles of good practice outlined in the guidance from INVOLVE (2006). It would have been difficult to do this with this project. The resources for the project were jointly funded by the University and the NHS Trust to provide my

supervision and therefore there was no flexibility to allow participants to have access to research resources (Caldwell et al. 2008).

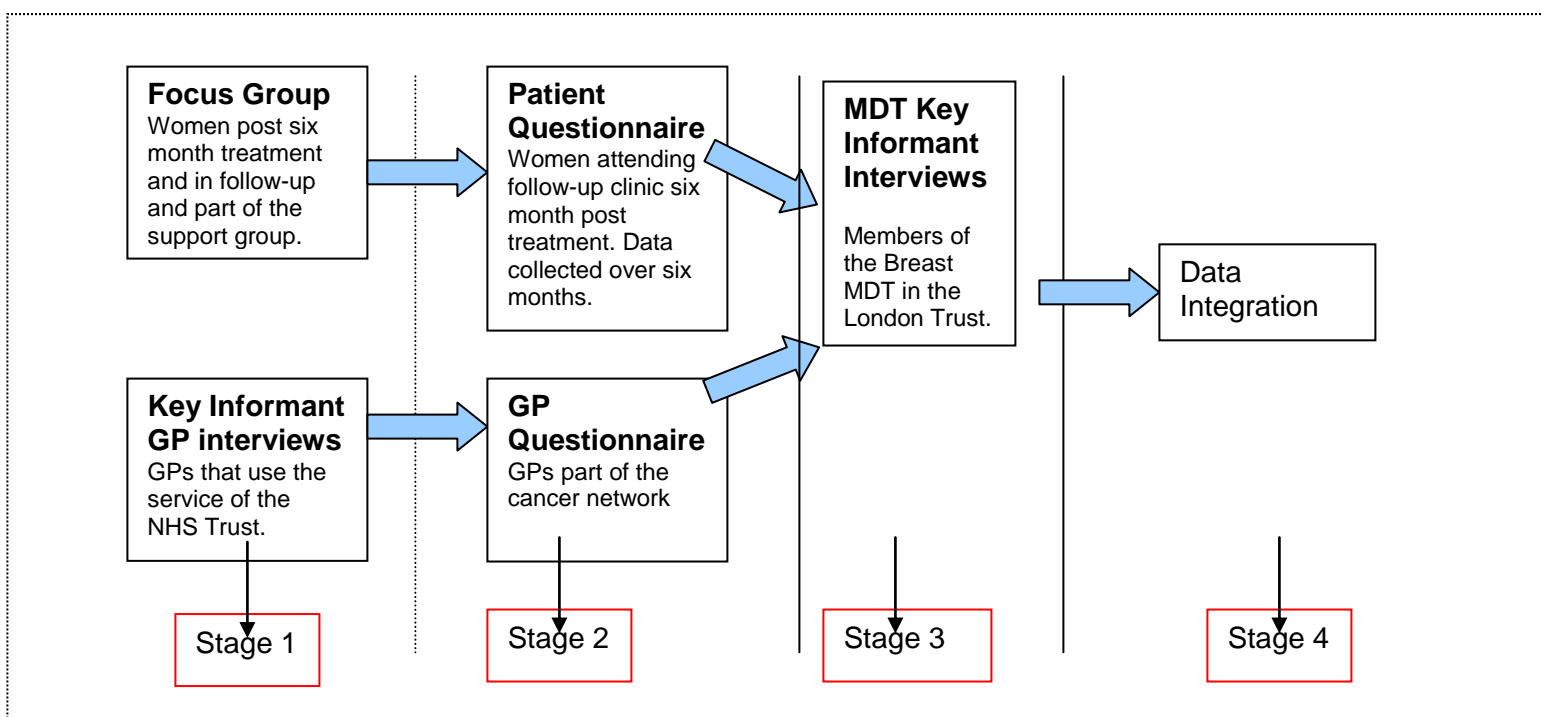
Nursing has to embrace a wide range of methodological approaches to investigate the diversity of service provision. Using combined methodology allowed for the limitations of each method to be highlighted and compared from different perspectives ensuring sophisticated rigour (Williamson 2005). I also needed to consider the impact of hospital politics and the broader cancer agenda at the time. Reflecting on the research and how actions would be developed was at a time when the trust merged services across two sites and clinical teams were being forced to work together in a hostile environment. Due to this there was a fear that the strategic agenda would influence the views of the stakeholders and the project may lose clarity.

#### **4.4.3 The study design**

A case study approach was identified as the design best suited to the aims of the research. The case study design involves an intensive exploration of a single unit of study (Burns and Grove 2005). Case studies are in-depth investigations not associated with a certain discipline of research and commonly use both quantitative and qualitative methods. Case studies allow the researcher to investigate situations and interventions, with information being collected from a variety of sources through different data collection methods in order to improve the understanding of the phenomenon (Burns et al. 2005). Case studies can, by definition, take place in a clinical context and can be carried out by practitioners in a way by which other remote forms of research cannot succeed (Sharp 1998). In this research case study methodology can be used as a creative alternative to other research methods to gain the key stakeholders experience of breast cancer follow-up clinics. By the stakeholders recounting their experiences of breast cancer follow-up

clinics and the meanings implicit in them it will assist developing a new model of care. According to Yin (1994) the case study design must have five components: the research question(s), its propositions, its unit(s) of analysis, a determination of how the data are linked to the propositions, and criteria to interpret the findings. This study used standard techniques for posing research questions and defining the unit of analysis. As the study design was focused on exploration and description, however, emphasis was placed on the purpose and aims of the study Zucker (2001). In this study, the unit of analysis was a breast cancer follow-up services in a North London Trust. This was the heart of the study with sub cases to capture the views of the other stakeholders; the women, the GPs and the MDT. These views would then reveal multiple dimensions of any one given case and added validity to the research process (Jones and Lyons 2004). The participants in the case study had a clear inclusion criteria and set time spans to collect the data (See Figure 1). The design of this case study had three distinct stages and utilized five data collection methods (Figure 1).

**Figure 1- The Research Design**



- Stage 1 - To develop two separate questionnaires for patients and for GPs, a focus group was formed with the local breast cancer support group for one questionnaire and local GPs were interviewed on a one-to-one basis for the other questionnaire.
- Stage 2 - With the themes generated from the focus group and from the interviews a survey of the users was developed and administered.
- Stage 3 - Key informant interviews were conducted with members of the MDT to enable the views of the team and their priorities in breast cancer follow-up to be heard.

One important benefit of multiple methods is in the reduction of inappropriate certainty (Robson 2002). Using a single method and finding a clear-cut result may delude the researcher into believing that they have found the right answer. Using other methods may point to different answers, which remove inaccurate certainty. This linear design of research allowed each phase to inform the next and enable method triangulation. The questionnaires generated quantitative data for statistical analyses but this data was enhanced by the qualitative accounts from the semi-structured interviews and focus groups. The research design had to meet the aims of the study to enable the stakeholders to collaborate and possibly implement a change in practice. Increasing the understanding of each other's values and perceived needs about breast cancer follow-up, with commitment to incorporate the views of the users, the GPs and the MDT, was vital to this research. This unique perspective had clear potential to contribute to improving the quality of care for patients.

#### **4.5 ETHICAL CONSIDERATIONS.**

The conduct of research not only requires expertise and diligence but also honesty and integrity. Ethical research is essential to generate sound knowledge for practice (Burns et

al. 2005). When humans are involved in research, care must be given to ensuring that the rights of those people are protected (Polit and Beck 2004) and therefore the research into breast cancer follow-up was submitted to, and received ethical approval from Local Research Ethics Committee. (Appendix 1).

#### **4.5.1 Choosing to participate**

Initial contact was made to the local Breast Cancer Support Group regarding the study and pointing out the value of their views in a group setting. A brief outline of the study including ethical clearance was given and ten women volunteered to meet as a focus group. Nominees were invited to attend and details of time and location were agreed. Prior to the breast cancer focus group, participants were given the opportunity to ask any questions they had, written consent was obtained (Appendix 2) permission to tape-record the session was sought and given, and a guarantee of confidentiality was made.

GPs were approached through the North London cancer network, and invited by letter (Appendix 3), including the Participant Information Sheet (Appendix 4), to be interviewed. Those agreeing to participate gave written consent (Appendix 2) prior to the interview, having had the opportunity to ask any questions they may have had and discussed any issues.

The survey participants (patients and GPs) in this research were informed by letter about the proposed study and given the option of participating and the right to withdraw at any time. (Appendix 5 and 6). To ensure truly informed consent a Participant Information Sheet (Appendix 4) was sent with the invitation letter. Participants for the patient survey were asked to attend clinic ten minutes prior to their consultation with the clinician to enable data to be collected. Before completing the questionnaire written consent was



obtained (Appendix 2), after the participant had the opportunity to discuss any issues and ask any questions. In seeking the views of GPs relating to the development of follow-up in the breast cancer services of the Trust, similar principles were applied. GPs who consented to participate returned the signed letter (Appendix 6).

For the key informant interviews, a presentation of the study was given to the team and participants requested. Those agreeing to participate gave written consent (Appendix 2) prior to the interview, having had the opportunity to ask any questions they may have had and discuss any issues.

#### **4.5.2 Protecting the participants**

To seek the views of the patients in this study the principle of beneficence and protection against compromise had to be considered. The diagnosis of breast cancer and its clinical management is life threatening and frightening to all patients. To develop a research project involving a vulnerable group of women who are already concerned about their clinic appointment might cause them further distress. Therefore, to protect the patients and prevent any psychological detriment, the questionnaires were administered in the outpatient clinic, by a member of the University staff who was also a registered nurse. I was available as the clinical nurse specialist and the consultant to offer advice and support if necessary for any patient completing the questionnaire.

During the research there were ethical dilemmas arising for me, during the focus group interview I became aware that some patients had found some aspects of their care unacceptable. To ensure trustworthiness and rigour within the research I had roles as a researcher, a human being and as a nurse (Spear 2006). As a nurse I was not required to administer practical nursing care but became aware of certain aspects of follow-up that were to influence future practice. In the light of beneficence, 'to do no harm' is an

important ethical principle and, with the assistance of MDT discussions and changes in practices following the research, the benefits of the research would outweigh any possible harm to the patients.

Each person has the right to privacy and the participants in this research study had the right to have their privacy upheld and their dignity maintained by ensuring that confidentiality was maintained. The identities of the participants were protected by adopting a range of strategies:

- Prior to conducting the focus group interview participants had the opportunity to discuss and agree the maintenance of confidentiality and ground rules were set.
- The master copy of the patient and GP participant list was constructed and coded and stored in a locked cupboard. The signed consent forms were collected in a separate folder and kept in the same locked cupboard. The data collected was entered into a computer programme under the codes for identification. The interview transcripts were also kept locked away for safe keeping (Burns et al 2005).
- The nature of qualitative research can make it difficult to maintain confidentiality. The small numbers and my closeness to the raw data can make it difficult to disguise the subject's identity (Burns et al. 2005). Orb, Eisenhauer and Wynaden (2001) recommend the use of pseudonyms, which were used in the reporting focus groups, GP and MDT interview' findings. The interviews were taped and the interpretation of the data from the discussions were sent to each member for clarification but their names were not used in the writing up of this report and related publications.

#### **4.5.3 Effect on the participant**

The main concern about the focus group was the effect the discussions would have on the participants again the MDT and GPs did not discuss personal accounts of an emotional

and threatening time in their life. Following the focus group many participants did say they found the discussions beneficial that their feelings were similar to others and therefore not alone (Eide and Kahn 2008). However, I was concerned about the effect the discussions about local recurrence, many years following diagnosis, caused many participants and the anxiety this could cause. Reflecting on a diagnosis of cancer and the threat to life associated with the disease - to relive some of the aspects of the care received would be distressing and therefore I needed to be mindful of this. In this study I was not certain about the impact of the discussions, for some focus group members the topics covered were beneficial but for others they were stressful. It is therefore difficult to predict topics that will be covered prior to the group meeting. In this study the issue of recurrence was the most distressing but as Mary had been treated some time ago for her recurrence and was now well again this gave the group some reassurance.

The group discussions and key informant interviews evoke stories, memories and opinions that would not occur if I had just investigated on my personal reflections. The discussions enabled the participants to talk and make meaning of their situation. The dialogue together may have led to a different type of understanding that may not have been achieved in singular interviews. For example not everyone had poor follow-up care in the focus group which encouraged discussions around what was defined as acceptable care. The GPs also discussed whether they would participate in follow-up which caused a heated discussion about the advantages and disadvantages of providing this care in the primary setting (Eide et al. 2008). By eliciting the participants' stories and the key informant interviews the importance and the worth of these stories were validated and I gained a deeper understanding of their experiences as patients and as professionals (Eide et al. 2008).

To conclude this small study demonstrates that there can be a number of difficulties during the data collection process. These include confidentiality, role conflict and impact of interviews/group work. As a nurse this did cause some conflict between my role as a therapeutic MDT member and a researcher however, my skills as a cancer nurse helped the participants discuss their experiences and deal with any difficulties encountered in 'telling their story.' Supervision from the university helped clarify my experiences as a nurse and daughter which may bias the views of the participants. However, to have coded the reflective diary or journal of my thoughts and preconceived ideas would have been useful in the writing up stage of the data. To try and divorce the role of the nurse and researcher is difficult to achieve as for this piece of work my role as a nurse enabled me to encourage patients to participate in research. This in turn then stresses it would have been false to use one's identity as a nurse to recruit the participants and then shed one's identity once the study began.

#### **4.6 SAMPLING**

The use of small non-random, convenience, or volunteer, sample (Polit et al. 2004), common in qualitative work, did not aim to establish a representative sample drawn from the population but rather to identify specific groups of people who either showed identifiable characteristics or lived in circumstances relevant to the social phenomenon being studied (Mays and Pope 1995, Tuckett 2004). Fielding (1993) describes the use of theoretical sampling as a specific type of non-probability sampling in which the objective of developing theory or explanation guides the process of sampling and data collection. Thus I as the analyst made an initial selection of informants, collected codes and analysed the data.

#### **4.6.1 The samples**

- Patient focus group - As the local breast cancer support group volunteers have a range of demographic variables e.g. age, type of disease etc, these factors were identified prior to the start of the discussions. Though not statistically representative of all women with breast cancer, their experience means that they have very important views about breast cancer follow-up. This minimized the possible bias arising from selecting a sample on the basis of convenience, which has potential for excluding some demographic variants. The twelve participants in this focus group comprised of the local breast cancer support group. This enabled the group to be as homogeneous as possible but its members were from varying backgrounds (Kitzinger 1995, Lambert and Loiselle 2008). Diverse backgrounds but similar experiences allowed me to gain maximum benefit from the different perspectives (Clarke 1999, Duggleby 2005). All women had received primary treatment for breast cancer between 1983 and 1999. Primary treatments were at varying hospitals across the cancer network. Four participants had cancer recurrence and one focus group member has subsequently died.
- Patient survey - The 111 patients surveyed in this study were selected from the clinical database. This sample was drawn from the clinic lists with a set criterion of six months from completion of adjuvant treatments. All patients were under the care of one consultant surgeon and oncologist. All patients were receiving care from one centre. The results therefore can be applied locally in catering for patient satisfaction and service development. The patient questionnaires were administered to all women who agreed to participate and were attending follow up clinics, during minimum period of six months post treatment. Men were not included as the number of men diagnosed was small and might have skewed the results. Women who were involved in the pilot study were not asked to complete the questionnaire nor were those currently experiencing recurrence and subsequent treatments.

- GP interviews - A GP focus group was carefully considered to elicit the views of GPs from which to develop the questionnaires. The purpose of bringing the GPs together would enable them to express and clarify their thoughts, as well as my thoughts around breast cancer follow-up. The cross discussion and the group dynamics could assist the GPs to address different aspects of cancer care, something which may not occur in a 'one to one' interview (Burns et al. 2005). However, to organise a meeting proved extremely difficult owing to clinical commitments. Therefore key informant interviews were planned between demographically different surgeries to generate the themes for the questionnaire.
- GP survey - The sample of 164 GPs, who were surveyed in this study, were selected from the cancer network list of GPs. All GPs used the services of breast units in the cancer network. The GP questionnaires were sent to all GPs and then a second questionnaire was sent in the post to encourage completion. GPs, who were involved in the pilot study, were not asked to complete the questionnaire.
- MDT Key informants - Professionals from various clinical and managerial backgrounds were interviewed to avail of their insight into breast cancer follow-up. Following the Calman-Hine report (DOH 1995) cancer care was coalesced into MDT teams. Each cancer site has a team at each hospital and for this piece of research the breast team was interviewed. This comprised of: (1) The Breast Care Nurse: a woman and in her mid forties. She had nursed for over 20 years and, as a clinical nurse specialist, had worked in breast care for more than five years. Previously she had worked in the community, an experience that gave her an insight into community care and the interface experienced by patients with other members of the Primary Health Care Team. (2) The Radiographer: who was a woman in her late 40s. She had practiced for over 20 years. Her main interest is breast disease, both benign and malignant, but retains other x-ray duties in different clinical specialties. (3): Doctor One was male and in his early fifties. He had worked as a consultant surgeon and now specialises only in

breast disease and its management. (4) The Ward Nurse: who was in her early 30s and was a junior sister on the surgical ward where the patients were nursed. She trained in the nineties and worked on the surgical ward for four years where she was a staff nurse. She had become a junior sister during the previous year. (5) Doctor two: was a male oncologist. Following Calman-Hine report (DOH 1995) where cancer was divided up into units and centres, the oncologist is based at the Centre and visits the unit weekly. The oncologist interviewed also visits the unit weekly and the treatment takes place at the centre. (6) Doctor three: was a man in his late 50s. By background he was a consultant based in the trust. He has been a member of the Trust board for over two years but continues to have a small clinical case load.

#### **4.6.2 Sample size.**

- Patient focus group – 12 members of the local breast cancer support group volunteered to attend the discussions. 12 members was a good number to enable the group to discuss aspects of care and all members to have a voice (Lambert et al. 2008).
- Patient survey - The 111 samples of patients was small and from one cancer network. Therefore the results are not generalizable, but can be applied locally for service development.
- GP interviews – 5 GPs were interviewed. They were from different surgeries across the London Borough.
- GP survey - The sample of 164 GPs who were sent the questionnaires were all the GPs who used a breast service in the cancer network. However, 46 (41.4%) GPs did not use the service of the NHS Trust involved in the research which left 65 (58.5%) GPs who did use this London breast unit. This is a small sample but a good representation of the local population of GPs using this service.

- MDT Key informants – I was able to interview all members of the MDT who come into ‘face to face’ contact with patients who attend the follow-up clinics. I debated also interviewing consultant radiologist and pathologists but this proved difficult to organise and they do not meet patient who attend follow-up clinics.

## **4.7 DATA COLLECTION**

As discussed previously five data collection methods were employed in this study, and these are presented below in the linear way in which they were utilized.

### **4.7.1 Focus Group Interview**

The focus group interview is a qualitative approach used to learn about population subgroups with regard to their psychological and sociological characteristics and processes (Sloan 1998, Lambert et al. 2008). I was well known to the participants as the Clinical Nurse Specialist involved in facilitating the support group. The facilitator’s background is important (Sloan 1998, Polit et al. 2004) as they must manage the time, without excluding participants, and encourage the mainstream discussion (Bulmer 1998, Lambert et al. 2008). It was imperative to encourage the group to share their views openly, and I needed both to understand and manipulate the interpersonal dynamics within the group. Behaviours such as monopolizing the discussion or remaining quiet (hiding), making negative comments and dictating the pace of interpersonal activity, can be managed best by those who have experience and knowledge of managing group dynamics (Hisrich and Peters 1982). In this setting, the experience of attending the support group and managing the monthly meetings complemented these management skills.

The presence of other research participants also compromises confidentiality of the research session (Kitzinger 1995). For example, in-group discussions with people, who attended other service providers’ discussions on how clinics were organised, were



interrupted with “you can’t complain, they all work so hard.” However, on the other hand, there were discrepancies in care and in issues pertaining to dignity in the clinic setting. Confidentiality was vital to encourage these discussions to develop without anxiety on the part of participants lest that their service provider would be aware of their expressed views which might result in the compromise of their professional relationship or care.

The focus group session was guided by the pre-prepared interview guidelines (Appendix 7), which had been informed by the key themes evident in the literature and by seeking expert opinion. The interview was tape-recorded and later transcribed, allowing subsequent review and reflection of the content of the interviews (Kitzinger 1995, Tuckett 2005, Mays et al. 1995). Taping the conversations helped to reduce information overload, as it can be difficult to absorb all the information during a focus group discussion. It allowed me to concentrate on facilitating the group within the guidelines, ensuring an environment that was conducive to group interaction (Sloan 1998). The women had agreed to meet in the evening in the postgraduate centre at the local hospital where the support group convenes monthly. This ensured that the nominees knew where to meet and felt comfortable with the surroundings.

The group reflected the process of developing a perspective or a position among a set of people (Reed and Parton 1997). They discussed aspects of care that were important to them and highlighted their fears following a diagnosis of cancer. This rich and personal data enabled me to develop the questionnaires from the patients’ perspective. During the focus group discussions, members had the opportunity to exchange and explore ideas (Beck, Trombetta and Share 1986) and they felt some degree of security in expressing their views in a crowd with spontaneity and candor (Beck, et al. 1986), (Nyamathi and Shuler 1990), (Lambert et al. 2008). This method extends beyond the ‘tick box’ (Bulmer 1998), and it provided data that was rich in human experience and a reflection of the real

life and experiences of the group members (Stewart and Shamdasani 1990), (Morse 2000). Reviewing the tape recording enhanced reflection on the interaction that had drawn upon the rich experience of the patients. Their very personal experiences helped me to explore all aspects of the issues being discussed - for example, the examination technique seemed to be an integral part of the follow-up appointment. However, by further questioning and by the interaction of different members there also emerged issues around continuity, dignity, fear of recurrence and care from the doctor. These aspects of care were discussed in relation to examination and they were found to be much more complex than I had first thought.

I had a pivotal role in relation to the data being generated. A difficulty lies in striking the right balance between an active and a passive role. I had to generate an interest in and a discussion about, a topic that was close to my professional, academic and personal interest, without at the same time causing a bias (Tuckett 2005). I needed to think critically through the dynamics of the group I knew, between my own feelings about breast cancer and the data emerging from the discussions. This critical thinking and self-awareness is a form of reflexivity (Burns et al. 2005) that allowed me to explore my personal feelings and experiences of breast cancer that could have influenced the study. As I was known to the group and was aware of some of the issues, it made me feel competent to understand and begin to understand the data and to feel less of an intruder in the group, than might have been the case if the interview was conducted by someone not known to the group. This allowed me to be relaxed and reassuring to the participants and to encourage them to tell their story.

Another important consideration in the selection of participants is always whether or not it is desirable for them to know each other. Pre-existing groups that have formed for some other purpose can allow the researcher access to established group dynamics, but

Krueger (1994) suggests that such group members will have established ways of relating to each other. Vaughan, Schumm and Sinagub (1996) argue that individuals who are brought together for the purpose of the study will be more inclined to talk freely and truthfully, uninhibited by the prospect of having to meet again. In relation to breast cancer follow-up the shared experience of breast cancer appeared to assist both the verbal and non-verbal communication.

The focus group interview was tape-recorded to enable meto participate in the group discussion and to observe and note the non-verbal participation (Krueger 1994), (Schroeder and Neil 1992), (Tuckett 2005). Butler (1996) points out that the problem in recording the session is the identifying of the voices, therefore field notes were used to assist in the transcribing of the debate.

#### **4.7.2 Patient Survey**

From the analysis of the focus group interviews themes emerged that informed the development of the questionnaires, which were then piloted on ten members of the support group. From the pilot study the questions were amended to ensure that they read correctly and so the questionnaires were refined (Appendix 9). Then, in the outpatient setting, questionnaires were administered to 111 women by professionally qualified staff. Prior to the outpatient appointment the participants were written to, requesting them to attend the hospital ten minutes earlier than the appointed time. This prepared the participants and allowed the completion of the questionnaire to take place prior to the consultation. Otherwise issues of bias may have influenced their thinking, having experienced a clinical appointment available time afterwards may have caused pressure and not have been easy for the participants to remain after the appointment.

The likelihood of subject bias can arise from a desire on the part of the participants to please or help the researcher or from uneasiness on the part of the researcher regarding observer bias and this may cause problems in the validation of the data. Therefore to eliminate this problem, independent health-care professionals conducted the interviews. The questionnaire requested the views of the participants but also noted some key demographic variables, and in addition clinical variables were collated from the case notes (Appendix 10). This helped to ensure reliability, validity and the possibility of identifying relationships between these variables (Robson 1993).

The data collection methods needed to be flexible. The data from the patients would need to be collected in such a manner that it would not interfere with a very busy clinic where both patients and clinicians had very little time to spare. Because the participants might be anxious to see the clinician, attempts were made to pre-empt the missing of booked appointments by writing to all the participants and requesting them to attend ten minutes prior to the consultation time. When considering the design, time taken to complete was a very important factor as it was essential that the questionnaire did not pressurise an already over stretched clinic.

The questionnaire used open-ended questions to elicit the women's feelings in relation to follow up. It also contained questions, the responses to which were measured on a Likert scale to determine attitudes of the respondents to breast cancer follow-up care and their views on possible future changes (Likert 1932). Scales were developed so that respondents could calibrate their views between 'strongly agree' to 'strongly disagree'. The results were then coded and entered into SPSS (Statistical Package for Social Sciences), a computer package that aided both the descriptions of the data and the correlations between variables.

#### **4.7.3 GP interviews**

The attempt to co-ordinate a meeting of different GPs who work in different localities proved impossible. Due to very busy caseloads, gaining access to speak with local General Practitioners alone proved frustrating. Therefore key informant interviews were organised with GPs, from different areas and from different practice sizes, to ascertain their views around breast cancer follow-up. To assist with the interview, key points from the literature relevant to breast cancer follow-up and issues from the patient focus group discussions were used as a guide to the line of questioning (See appendix 8).

#### **4.7.4 GP Survey.**

The themes from the interviews assisted with the drafting of the GP questionnaire. Ten GPs were piloted and their comments were incorporated into the questionnaire. (Appendix 6). Then the questionnaire was sent by post to all GPs in the area. The network configuration means that many GPs, who do not use the breast unit regularly, service the area. It was increasingly difficult to ascertain who the consistent users were. Therefore, to reduce sample bias, all GPs were questioned in the knowledge that many of them would not use the service. The GPs were contacted in writing twice, enclosing the questionnaire and an addressed envelope to encourage completion and return. Included with the questionnaire was a letter explaining the research project and a consent form. The questionnaire requested information such as type of GP practice, whether a singlehanded or a group practice, and the number of patients registered. It was thought that these variables might influence views on breast cancer follow-up. Subsequently, I felt that the questionnaire should have included the length of time the GP had been in practice, which also may have influenced their opinions on follow-up and their own ability to become involved in this aspect of care.

As with the patient questionnaire Likert scales were used to determine attitudes to breast cancer follow-up and to ascertain their views to possible future changes (Likert 1932). Scales were developed so respondents could calibrate their views ranging from 'strongly agree' to 'strongly disagree'. The results were then coded and entered into SPSS, a computer package that aided both the descriptions of the data and the correlation between variables.

#### **4.7.5 Data Collection – Key informant interviews for the multi-disciplinary team.**

As with the GP interview I used an open-ended question to commence the key informant interview and proceeded to address key points from the literature around breast cancer follow-up and government policy influencing the management of breast cancer. Open-ended questions were used to encourage freedom to narrate their views and from there, the interview focused on elements that were significant to the interviewee. In order to encourage the interviewee, I was silent during most of the interview, just nodding and saying "Yes", "I see", "Can you tell me more about..." Furthermore, to ensure clarity and understanding of the context, I repeated responses during the interview (Patton 2002). Each interview lasted about 60 minutes and was tape-recorded, and was transcribed verbatim. I listened to all the interviews while reading the scripts to ensure accuracy and make corrections and additions as appropriate.

### **4.8 DATA ANALYSIS**

In designing the tools discussed in the previous section, the methods of analysis were determined and developed in order to be able to enhance data integration.

#### **4.8.1 Focus group and interviews.**

The transcripts of the focus group, the GP and key stakeholder interviews were analysed using thematic analysis. This is a well-known method for a descriptive analysis of text. It

is performed step by step in order to describe prominent themes (Krippendorf 2004) (Morse and Field 1996). All interviews were drawn together into one text, which was then divided into units and then coded by themes and sub themes. All the codes used were linked back to the original units. All codes were based on similarities and differences and were used to form the themes. These were reviewed several times until they were finally organised into themes and sub themes. The themes were then discussed with my supervisors. Both supervisors are academics with a registered nursing background and with various experiences and have previously participated in similar research.

#### **4.8.2 GP and Patient Questionnaires**

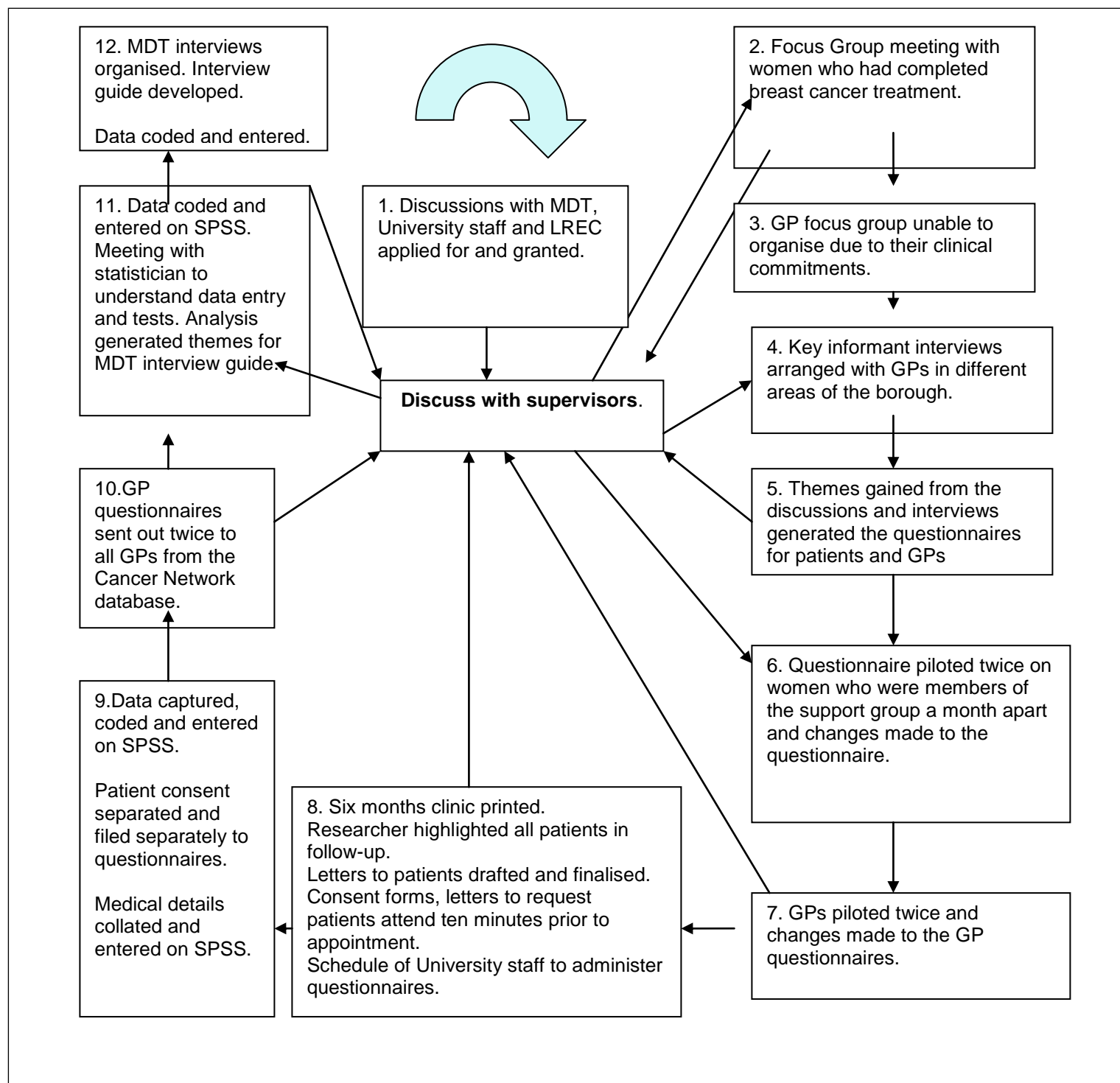
Variables were defined and a code-book developed that included abbreviated variables identifiers, a description of the variable response codes. The code-book enabled me to maintain control of the data and to facilitate understanding. For example the abbreviation variable 'Q6 Ppse' coded the answers for the purpose of follow-up. Each coded response tallied with the Likert Scale (1932) used in the questionnaire and allowed for the collection of numerical data. Anonymous GP and patient data were entered both on the computer and on a disc to ensure backup, and was printed out and cross referenced to ensure that clean and accurate data had been collected and entered accurately. Any missing data was identified and coded using the letter 'Z'. Any GPs who responded, but were not actually using the Trust services in the study, were excluded from the analysis, thus confining the sample to GPs who were in a position to provide an informed response on the case study site.

The samples of patients and GPs required the frequencies of the descriptive variables to ensure that comparisons could be made. Size of GP practice population, whether group practice or not, was an important variable on which to make comparisons. Age, ethnicity,

social class, disease stage and treatment were also important elements of the patient questionnaire. Parameters were taken from previous research (Pennery et al. 2000), (Grunfeld et al 1999) and a university source of statistical advice was used. The data was inputted and I analysed it with support from a statistician. Once the data was inputted a descriptive statistical analysis was undertaken to determine patterns and trends that emerged from the responses. Cross-tabulations were performed, and where appropriate tests to determine the existence and strength of any association between demographic variables and responses were carried out.



**Figure 2 - Audit Trail.**



## **4.9 STRATEGIES TO ENSURE RIGOUR.**

A range of strategies to enhance the rigour of this study was used in this study. At the beginning of the project a meeting was constructed with the MDT regarding the projects aims and objectives. The research supervisors were included and application to the Local Ethics Committee (figure 2 number 1). This ensured the clinical team was in agreement with the project and there was clarification of roles.

### **4.9.1 Ensuring dependability and credibility**

In the qualitative stages of the study I was constantly engaged with the data, using a reflexive process to confirm the interpretation of the links between them. Verbatim examples of participants' comments in the written accounts of the findings were used to identify the interpretive process and reflect the tone of the responses and demonstrate credibility. A transparent process of reflexivity was adopted in order to minimize researcher bias. As from the audit trail (figure 2 point 2) the focus group met from volunteers of a local breast cancer support group. A focus group of GPs was more difficult to organise (figure 2 point 3) so key informant interviews were organised (figure 2 point 4). I met regularly with my academic supervisors and would reflect honestly and openly on my own ability to be unbiased (Burns et al. 2005). The reduction of bias was also enhanced by respondent validation. The discussions were transcribed and given back to the members of the focus group as well as the MDT and the GPs. They checked for accuracy in representing their experiences and views of breast cancer follow-up and I amended them where necessary (Bryman 2001). I recognised the impossibility of absolute objectivity and through a reiterative process of reflection ensured that interpretation of the findings represented the stakeholders' perspective on the key issues for them in relation to breast cancer follow-up, rather than my views and experiences in breast cancer nursing. Therefore I attempted to bring together the process, the data from multiple sources and

the findings to enable the reader to engage in the interpretive process and confirm the findings.

The group discussions and interviews were recorded, transcribed and fed-back to participants to enhance dependability, and non-verbal communications were also documented, including the raw emotions expressed by respondents' raised voices, by crying and by silences (Roberts, Priest and Traynor 2006). The audit trail of the research over time was a vital activity throughout the time that the study was undertaken. The note keeping, the plans and the process, through which the results were reached, were all needed to demonstrate dependability. All transcripts were retained, revisited at intervals, linked to other data sources and discussed, in depth with academic supervisors. (Morrow Haverkamp, and Ponterotto 2005).

This research, as a case study, does not attempt to generalize outside of the study setting, but in providing information on the construction of the focus groups and interviews, and the use of a transparent interpretive process a degree of transferability could be achieved. The themes from the discussions were developed to generate the patient and GP questionnaires. (figure 2 point 5).

#### **4.9.2 Internal validity of the questionnaires**

As in the audit trail (figure 2 point 6) the questionnaires were piloted with patients and GPs to ensure validity and make certain that the questions elicited answers that were required to address the research questions. Pilot participants were asked to complete two questionnaires one month apart and the responses showed a similar pattern thus giving reassurance as to the test-retest reliability (Roberts et al. 2006). However, I was aware of the limitations of this approach in as much as the experience of responding to the first test might influence responses to the second test (Bryman and Cramer 2004). Internal validity

was demonstrated through conducting a pilot study that ensured content validity for both the patients and the GPs. Internal validity was also measured by testing relationships between the variables and the responses.

#### **4.9.3 External validity of the questionnaires**

Punch (1998) outlined how the situation and samples of the study must be representative of the population and its clinical environment with the relevant variables to ensure external validity. In this study the patient questionnaires were administered in a breast outpatient clinic as in the audit tool (figure 2 point 7) over a six month period. The clinics were organised in a uniform way which is replicated across the U.K. The age group varied but was in line with national age groups of women who were diagnosed with breast cancer. All women were treated according to national guidelines and were thus representative of the population. The GP sample was also representative as they included all GPs from the local cancer network list of GPs. All data was coded and entered on statistical package SPSS. Following discussion all the way along with university supervisors and the statistician the data analyses developed the themes for the MDT interview guide.

#### **4.9.4 Triangulation**

Triangulation was another way of enhancing the rigour of this study. This allowed for the engineering and exploring, required to investigate the case in question, and to gather a range of data in both depth and breadth, from various sources. The use of method triangulation has widespread support for enhancing the credibility and dependability of qualitative research (Tuckett 2005), and any potential bias from one method could be counterbalanced by another (Tuckett 2005). Between-method triangulation was applied to this study and the in depth interviews with key people and the focus group (both qualitative methods) generated themes for the questionnaires. The surveys of patients and GPs entailed questionnaires completed by people using the service, generated data that could

be integrated with the data generated by qualitative methods to strengthen the analysis and interpretation. While this may be complex, the application of a 'between' approach promoted confidence in the findings. The use of questionnaires and structured interviews facilitated the collection of numerical data that was used to add breadth to the depth of the qualitative findings. Therefore, by integrating different methods and analyses, the weakness of one approach was minimised. Quantitative data from large studies have major strengths but, with tight control, quantitative studies may not capture the context of the situation and this may lead to bias and invalidity of the data. Therefore the strengths and weaknesses of quantitative and qualitative data were complementary in this study.

#### **4.10 REFLEXIVITY**

Reflexivity is being aware the degree of influence that the researcher exerts, either intentionally or unintentionally on the findings (Jootun, McGhee and Marland 2009). This is crucial in nursing and in this research as I knew the participants. Primeau (2003) suggests that reflexivity enhances the quality of research as it enables the reader to understand how the position of the researcher affects all stages of the research process. Parahoo (2006) defined reflexivity as the continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence and those of the participants, which may affect the interpretation of their responses. This was so pertinent to this research as I was a specialist nurse and the daughter of a patient diagnosed with breast cancer and therefore had to recognise that I was part of the social world under study (Jootun et al. 2009). I found that there was conflict trying to balance the role of nurse, researcher and daughter and this will be discussed in turn and the impact this had on the research study.

#### **4.10.1 Relationships with the participants.**

During the research project an awareness of coercion was discussed frequently with the academic supervisors and every effort to avoid this was made. However, I knew the members of the focus group and had a professional relationship with this set of patients. It was my concern that they might have felt obliged to consent to being interviewed (Johnson and Plant 1996). To try and negate this it was agreed that university staff would interview the main cohort of patient in the outpatients department.

Reed and Proctor (1995) have highlighted the debate of the researcher's relationship with the study participants. They consider the researcher occupies one of three positions: 'outsider', 'hybrid', or 'insider'. The 'outsider' is a researcher who with no professional experience and a visitor to the area of study. The 'hybrid' is a researcher who undertakes research into practice of other practitioners and is familiar with that research area. The 'insider' is the actual practitioner as a researcher looking into their own and known colleagues' practice. Reed et al. (1995) felt this was a continuum, with the researcher moving backwards and forwards along it as they engaged with the research process. I considered myself placed between 'hybrid' and 'insider', as I was working in the acute setting only and therefore not known to the GPs I had completed my first degree sometime before which included reviewing the literature around breast cancer follow-up. So as I entered the research process I recognised I held preconceived ideas towards breast cancer follow-up but felt that my professional background helped me communicate effectively with the participants both patient and professionals. I did recognise this could be viewed negatively and that I could be construed as forcing the data but during the research process this was discussed with the participants, and my role had been transparent in revealing my background and reasons for decisions taken (McGhee, Marland and Atkinson 2007). However, while striving to see the participants' interact in the focus group and the interviews with GPs and the MDT, from the experience I had as a

cancer nurse, I was able to construct meaning that may not be apparent to an outsider (Jootun et al. 2008).

The interviews with the MDT did not pose such a threat to the participants as the subject discussed were not accounts of their personal life. However, working in the environment where I was a nurse had both positive and negatives aspects relating to the data collection. I had an understanding of the routines, jargon and the local trust and political cancer agenda. This assisted when interviewing the MDT to participate in discussions with the medical director, GPs, consultant and nursing colleagues to gain rich informative data. At a time in cancer policy where DOH (1995) was instigating the development of cancer units and cancer centres many MDT's were feeling vulnerable and threatened. As I was known to the team I did not create suspicion at a sensitive political time (Coghlan and Casey 2001).

I found that one of the difficulties in collecting data and working in the environment was the issue of loyalty. When GPs or patients discussed some aspects of care they were unhappy about I wanted to give explanations as I felt a certain loyalty to the team I worked along side. When giving some informal feed back to the clinical staff it was very sensitive and needed to be handled carefully to manage this tension (Coghlan et al. 2001).

#### **4.10.2 Dealing with participant's anxiety.**

During the data collection I found the focus group difficult as some participants became very emotional describing their experiences. The impact of in-depth discussions within the focus group caused some participants to cry. As a novice researcher this may have caused concern, however, my nursing background allowed me to use another set of skills to assist the discussions and due to my established knowledge of breast cancer I was already prepared for some of the issues (Beaver, Luker and Woods 1999).

#### **4.10.3. Concerns about confidentiality.**

Maintaining confidentiality when reporting the findings was a concern for me, and this was also a concern for the participants but mainly when reporting to the health care professionals (Johnson and Macleod Clarke 2003). This conflict caused concern as the route of access to the patient participants was through one of the consultants. This 'gate keeping' (Burgess 1984) is common in qualitative research and can be inherent in research design (Ersner 1996). In collecting data regarding breast cancer follow-up and reporting back to the MDT I had to balance the privacy of the individuals against the interest of society (Johnson et al. 2003). Mary explains, during the focus group, how she did not recognise what cancer recurrence looked like. This caused me some distress that patients did not know what the key signs of cancer recurrence were, but I did not want to break confidentiality. In an informal feed back session to the MDT I highlighted to the team their role in giving patients information both in treatment choices and to discuss with patients reporting any changes that may cause concern such as recurrence.

#### **4.10.4. Role conflict.**

I found conflict between collecting data and being a nurse and clearly it was difficult to shed my previous knowledge and experience when collecting the data. Charmaz (2000) states that researchers should openly acknowledge the influence of prior work they have completed or experienced which may affect their perspective of data collection. For this research project it was with the assistance of the university supervisors that the themes came from the data and not from preconceived ideas.

Personal reflexivity involves a relationship like that of clinical supervision (Dowling 2006). I utilised my research supervisors to identify assumptions and past experiences in order to



'bracket' them or put to one side (Rolls and Relfe 2004). During the tape recorded interviews I typed the interviews myself to immerse myself in the data and kept short notes about my assumptions. For instance when discussing with the GPs some were keen to be involved in breast cancer follow-up which I found surprising as my experience in the past did not think that was likely. On reflection I now wish I had also coded these comments too, so my differing thoughts could have been compared with the views of the participants, however, the real effect of the interviews did not impact on me until the writing up stage. My experience of follow-up and being a daughter of a mother who attended breast cancer follow-up clinics held my own beliefs and bias about how follow-up should be organised. This knowledge of breast cancer follow-up was utilised to illuminate important meaning to the data (Dowling 2006) and myself and the participants seen each other as partners which is particularly relevant in research involving sensitive issues such as cancer.

My clinical knowledge base also conflicted at times of being a nurse or researcher. For example Ellen explained that she does not practice breast awareness as follow-up now provides the 'official check'. I wanted to discuss at length the importance of being breast awareness and felt guilty about not being able to help but felt it may have conflicted with my role as data collector (Johnson et al. 2003).

As a nurse, I also struggled with the stories being told and not able to help or intervene to make the experiences the participants were having better in some way. I had a feeling of helplessness. As I was known to the focus group I fostered an empathetic approach trying to develop closeness and also a social distance. This is often called "detached concern" and was considerably challenging. As a nurse, I was trained to help and assist patients and to hear how some women were treated in the follow-up setting was extremely difficult to remain the impartial data collector and their stories challenged the very essence of my professional code of practice (Johnson et al. 2003).

In conjunction with the focus group I also found the key informant interviews difficult to remain impartial. One breast care nurse described providing good care as 'the stuff of magic'. If I had not been an experienced breast care nurse would I have experienced the level of anxiety I had during that interview?

Interestingly I had been a cancer nurse in specialist practice since the early 1990s. My knowledge base was that of cancer treatments and aetiology with a literature review for my first degree around follow-up and the development of nurse led services. At the beginning of the research process I had read latest cancer policy and new treatments which I was already quite aware of in the clinical area. It was on reading other aspects of psychological support and meeting the participants needs that an awareness of how narrow my horizons were and when advised by university supervisors to broaden my knowledge to the social science literature with long term chronic conditions my theoretical knowledge increased to issues I may have been oblivious to, rather than causing bias and affecting analysis I stepped outside my nursing perspective. For example the importance of cultural issues in patients adhering to treatment plans or making choices relating to treatment, did not impact on my every day clinical role. However, on reflection all social interactions affect decision making and now this does influence my clinical care (Hewitt – Taylor 2004).

#### **4.11 SUMMARY**

The impact of a diagnosis of breast cancer and the views of all the stakeholders regarding follow-up in particular has not previously been documented. A qualitative approach was used in this study to seek the views of all clinicians with the experience of these women and their views on, and needs in relation to follow-up. The qualitative methods were used

to describe the experiential aspects of the research, while quantitative methods were be used to measure other variables (Morse et al. 1996) (Polit et al. 2004). No studies to date have included the voices of the patient, the GP and the MDT as a group (Allen 2000, Pennery et al. 2000).

The main challenge in the research was to integrate the data from the interviews, questionnaires and focus group discussions. There appeared to be much overlapping but it produced rich data, which contributed to a clearer understanding of the complex multifaceted issues pertaining to breast cancer follow-up. Morse (2002) emphasizes that the multiple methods of a single study, to explore a complex phenomenon, enhances analysis and broadens conceptualization. The methods used were integrated to account for the different views of the stakeholders. The experience of breast cancer follow-up was brought to life by the data collated from the focus group and key informant interviews (Koch 2006). From the literature a diagnosis of cancer is associated with death and causes fear, panic and psychological distress after a breast cancer diagnosis (Costanzo et al. 2007) (Amir et al. 2002). This research design needed to incorporate tools to capture the views of all the stakeholders, which rely on descriptions, interpretation and clear measurement. The use of different methods produced a process by which follow-up, as it now stands, guided an exploration of the patients and clinicians' feelings about follow-up and the key issues around breast cancer and its management. Throughout the research an awareness of reflexivity was constantly discussed with the research supervisors to ensure confidentiality, allay patient anxiety and an awareness of my professional relationship and the participants. This data collected from the focus group highlighted the important elements – such as continuity of care and seeking information - of follow-up and important to be discussed in interview and questionnaire format. The focus group added comments on the structure – such as time in the consultation and the bedside manner of the doctors - of follow-up and on further important aspects of care for all stakeholders. The

focus group discussions meant that the views of the women who use the service were central to the research and the development of a new service. From these methods the convergence of key aspects of care across focus group discussions, interviews and questionnaires ensured rigour and a greater trustworthiness of the findings (Lambert et al. 2008).

## **CHAPTER FIVE**

### **QUALITATIVE FINDINGS**

#### **5.0 INTRODUCTION**

The first and third stage of this study employed qualitative methods to elicit information through a focus group interview for patients, individual GP interviews (Stage 1) and key informant interviews of the clinical team (Stage 3). In this chapter the findings of these stages will be presented. As explained previously in chapter four –

- The focus group comprised of twelve women treated for breast cancer at any Trust but at least six months out of treatment and a member of the local support group.
- The GPs interviewed were GPs in the locality who use the breast service of the NHS Trust.
- Interviews were conducted of the MDT and the medical director of the Trust caring for the women diagnosed with breast cancer in the NHS Trust.

#### **5.1 RESULTS OF THE PATIENT FOCUS GROUP AND THE GP KEY INFORMANT INTERVIEWS.**

##### **5.1.1 The key themes**

Five key themes emerged from the focus group and GP interviews. The GPs and patient group had similar themes. However, the GPs also discussed issues of shared follow-up care with the hospital. The themes are presented in Table 1.

**Table 1: Themes and sub-themes – Focus group and GP interviews.**

<b>Reassurance</b>	<b>Continuity of care</b>	<b>Process of follow-up</b>	<b>Communication</b>	<b>Shared Care</b>
Certainty	Fragmentation	Integrity	Style of communication	Willingness
Validation of 'wellness'	Familiarity	Vulnerability	Nature of information	Mode
		Examination	Opportunity to share	Finance

### **5.1.2 Reassurance**

The patients who attended the focus group discussed the importance of follow-up visits in providing re-assurance. Two sub-themes emerged in relation to this – certainty that the cancer had been successfully treated and an official validation of their state of 'wellness'. A diagnosis of cancer may invoke uncertainty, fear and loss (Leydon et al 2000). It is an extremely traumatic experience. Most people with cancer are vulnerable, hypersensitive and afraid of dying (Jensen, Back-Pettersson.and Segesten 2000). Furthermore, an outpatient system of follow-up has been identified as a cause of stress for some patients (MacBride and Whyte 1999). The word cancer is a frightening concept in our culture and adjustment is partly directed towards living with the fear that the disease will recur. Women in this study expressed concern in this regard and talked about their need for reassurance that they remained well, and the certainty that the cancer had not recurred. They welcomed their regular checks at the hospital and wanted 'official' confirmation that they were in good health and that there was no sign of cancer. At a number of points during the discussion, the group raised the issue of the follow-up as being a reassuring component of care. Jane pointed out that:

*'You know every three months you will be seen. I feel much better for it'*

(Jane).

Another participant highlighted how:

*'If there is anything untoward they will find it there and then the speed with which they will then follow it up is hopefully going to be quick'.*

(Anne).

They also talked about the need for an 'official' check, which made them feel secure. They described the examination by the doctor as an important part of the system. It provided security and peace of mind. Ellen summarized the view of many participants when she stated:

*'Whatever, it puts your mind at rest, perhaps given you a false sense of security, but you know you're being officially checked for lumps'*

(Ellen).

Another participant spoke positively of:

*'Someone is keeping an eye on you....'*

(Deidre).

Women in the focus group felt that appointments were reassuring in knowing that, clinically, there were no problems detected and this is vital for hope (Leydon et al 2000). Breast cancer has been seen in the literature as a challenge both in new diagnosis and in the follow-up setting (Luker, Beaver, Leinster and Owen 1996). Therefore without an understanding of the meanings that individuals ascribe to their illness, and of how they cope with that illness, attempts to assist patients would be ineffective. These aspects of care need to be incorporated into developing systems of breast cancer follow-up services. The recent publication 'The Supportive and Palliative Guidance' (National Institute for Clinical Excellence 2004), discusses the importance of rehabilitation and psychological assessment following a diagnosis of cancer however, during the focus group discussions

psychological assessment was not discussed but the fear of the cancer not recurring was. The need for reassurance described by the women in this study demonstrates the anxiety they experience and how their need to deal with this anxiety is an essential element of their aftercare. NICE Guidance (2002) to reduce follow-up and local cancer networks to design follow-up services in their areas need to consider the role of 'examination' in their systems which is in incongruent with the use of telephone follow-up (Beaver et al. 2009).

Likewise, GPs felt that improved confidence was the real benefit of attending follow-up clinics. When considering hospital based follow-up, the GPs felt that seeing the experts was the most important aspect even with the disadvantage of having long waits in clinic. One of the participant GPs explained:

*'I have a patient who has been discharged from the hospital (and) now feels bereft. She still comes to me in February when she would normally have her check up.'*

(Dr C).

Linked to this was the view that the follow-up clinic provided a focus for the provision of psychological support and Dr T highlighted:

*'...also the importance of psychological support for the patients.'*

(Dr T).

### **5.1.3 Continuity of care**

Participants highlighted their need for continuity of care and clearly articulated the benefits of this, but felt they often experienced what they perceived as fragmented care. Locally the clinics are organised in such a manner that the consultant will see all the new patients



or people with a changed clinical status during their follow-up period. Those women, therefore, returning for follow-up appointments with an uncomplicated recovery, would not see the consultant, but would find themselves meeting with another junior member of the consultant's team, who would probably be a different person at each visit due to the rotational nature of junior medical staff. The participants appeared to understand how the follow-up clinics were organized, but expressed the need to see the same person. The women described how being seen by different doctors prevented them building a patient-doctor relationship and they felt disturbed when a doctor had to read copious notes and ask the same questions. Anne expressed her sense of frustration when:

*'Every single time I go, someone has to get this file – three inches thick – and they've to ask you the same questions.....'.*

(Anne).

Several participants were able to explain the benefits of seeing the same person and found comfort in the knowledge that the doctor was familiar with their case. Ellen discussed how she thought:

*'... the most important aspect has got to be the continuity of care. Whether it's a consultant at least the same doctor so you can build a rapport.'*

(Ellen).

This desire to build a relationship with a key person was something that a number of the women spoke about:

*'If you had someone, same person, even though they see lots of people  
in the meanwhile, you have something to build on.'*

(Anne)

Joan spoke emotively about the need for familiarity:

*'..... even if you were to see the same follow-up doctor each time so  
you could build a relationship. It's like going to your GP. I like going to  
the same GP all the time because they know me. They get to know you  
... ..*

(Joan).

In line with Cox and Wilson (2003) the participants of the focus group identified the importance of continuity of care following such treatment, and they reported that they preferred to build a relationship with the professionals they dealt with. When a woman faces uncertainty related to a chronic illness, her belief that she can control the outcome of the illness and her ability to do so may be adversely affected (Dirksen, 2000). It can be argued that the current organisation of follow-up care, as found in the study setting, does not facilitate this level of support, which requires the development and nurturing of a therapeutic relationship over time. The findings from the focus group indicate that women do want to build a patient-doctor relationship and that this would enhance their ability to have confidence and to cope with their condition. Dirksen (2000) suggests that a woman's belief in and use of self-control skills in developing a pro-active survivorship should be supported.

Similarly to the patients GPs also viewed continuity of care as beneficial, with one describing how:

*'To see the same person instils confidence in the patient.'*

(Dr R).

However, another GP pointed out that continuity does not always happen in the hospital breast clinic:

*'I feel that continuity is paramount. The majority of our patients say they see a different doctor each time and had to go over all the history each time.'*

(Dr J).

This echoes Anne's point earlier.

Possibly, in light of the close working relationship between GPs and practice nurses and the role of the specialist nurse in the MDT, one GP expressed his confidence in the breast care nurses seeing the patients in follow-up.

*'I would feel totally confident in the specialist nurses seeing the patients. They know the patient and their history.'*

(Dr A).

#### 5.1.4 The process of follow-up

Three key sub-themes were evident in relation to the process of follow-up, the women's personal integrity, their vulnerability and the way in which the clinician conducted the examination. In follow-up, as care is currently organised, women experience breast examination by different doctors and their concerns regarding privacy and dignity are intrinsically linked to this examination technique. In recent decades patients' rights and ethical issues in health care have been in focus. Patient integrity is one of the important aspects of ethical reasoning (Beauchamp and Childress 2001) and nursing care. The patient is vulnerable and has a right to privacy and integrity. Integrity is also a key concept in individualised care planning and is described as being part of a human being. It includes privacy, autonomy and the values which the person espouses (Beauchamp et al. 2001).

During the focus group discussions, some participants became very emotional when discussing instances when their integrity had been breached. Whereas most women would dress in private Jane highlighted how:

*'... you get dressed while the doctors and nurses (are) there'.*

(Jane).

Several women discussed how it made them feel - frustrated and angry:

*'I was trying to get undressed she was trying to examine me. I said hang on, let me get undressed first I felt like... (J. quite tearful).... I'm wasting my bloody time coming here.'*

(Joan).

These women describe vulnerability and emphasise the importance of privacy during examination. Patient integrity is one of the important aspects of ethical reasoning (Beauchamp et al. 2001) which clearly underpin the nature of care. When this integrity is breached it adds to the stress and anxiety that these women encounter. However, this experience was not shared by the entire group. Kim described a very positive experience when, as she explained, the doctor was in another room and they did not have to get undressed in front of anyone:

*'Now mine's totally different. The doctor in one room, a proper examination....'*

(Kim).

Similarly Jane reported a positive experience in which:

*'In the clinic. You get undressed, it's all very tasteful'*

(Jane).

The group commented on the process of examination and the possible variations in technique. The women were often judgmental about their examinations and were able to demonstrate the parts of the assessment which, they felt, were good and those which were not. Joan clearly described how, when she was examined the consultant:

*'He comes in and asked how you are? Stands in front of you, examines you all around. You lie back and he examines both breasts. Asking you all the time have you any worries? How do you feel?...'*

(Joan).

She went on to negatively compare this with an examination carried out by another member of the team:

*'I'd never seen her before then she decided to put her hands around me, said ok get dressed. She just run her hands along it (mastectomy scar) like that, just walked away and started writing on a bit of paper'.*

(Joan).

Mary in a similar way appeared to view her consultant's examination technique as the 'right' one and described how she would:

*'...Sit down on the couch first and raise your arms. Then he'd lay you down examine the breast for quite a long while and over the other side and you sit up listen to your chest.'*

(Mary).

It can be suggested, therefore, that a standard examination technique would go some way in alleviating women's concerns, and enable them to have confidence that nothing is being missed. In addition to this a relationship that has a degree of continuity would build confidence in that women could feel that their clinician 'knew' them as an individual rather than simple as a 'case'.

### 5.1.5 Communication

The women who participated in the focus group all recognized that communication between them and their clinician was important. Three sub-themes relevant to communication emerged the style of communication, the nature of information being imparted and the opportunity for them to be able to share their feelings and concerns.

Doyal and Gough (1991) discuss the idea of two basic human needs – health and autonomy. Autonomy is closely linked with self esteem and the earning of respect. Low levels of autonomy and low self-esteem are likely to be related to ill health. Over recent years communication and information have been increasingly considered important in helping people to cope with cancer (Fallowfield, Hall Maguire, Baum and A'Hern 1994) (Coulter 1998), (Ford, Fallowfield and Lewis 1995), (Meridith et al 1996). The importance of information at the time of diagnosis and accurate information about the disease and about new treatments in the future were an issue of debate in the focus group. At diagnosis the amount of information and the sensitivity of its delivery were discussed at length: with Jane describing how:

*'I had to know everything, the worst and the good. I was hooked then. I got everything so I knew what to expect. The side effects of the chemo and the frightening statistics - the survival rate you know'.*

(Jane).

Her need for information however was not met with the sensitivity that she needed, and she was obviously distressed and was crying when she related how:

*'I saw the breast care nurse and another doctor. I sat down he said I've got the results, it's cancer.' em. He was very young. Very matter of fact. He said it was a very large tumour, we need to chemo – lose your hair. That's what silly hats are for and I'd just thought I'd got lost at some of the things (the doctor was saying). He said come back and see another doctor. At this time I was bawling. He said cry as much as you want to now. He said when you come back on Thursday the other doctor will explain what kind (of treatment) you need, lots of aggressive treatment..... I could not believe how insensitive he'd been that you go back and you're told'....*

(Jane).

Yet the lack of sensitivity in the way in which bad news was communicated was not a universal experience, on the contrary Anne described a very positive experience in which the doctor demonstrated a high level of sensitivity and awareness of the emotional aspects of the diagnosis, whilst establishing a therapeutic relationship with both Anne and her husband:

*'My doctor was absolutely wonderful. He sat down. He was calm. He drew me a diagram explained everything. I'd gone on my own. He said come back next week with my husband. We had four appointments in a row. He asked me whether I had any questions. He spent time with me. He listened to my options, what was best for me. We agreed and compromised'.*



(Anne).

The women highlighted their reliance on the follow-up appointment in relation to detection of new symptoms and clarifying information related to their disease.

*'Because at seven years I would have been discharged I would loved each one of you to have seen it (recurrence on the mastectomy scar). No way would I have ever seen that. To this day I could not believe he (the surgeon) saw it. I had lots of questions, especially about Tamoxifen and other drugs'.*

(Mary).

Patients receive information from different sources about breast cancer and some of this may be conflicting, and the clinic appointment can viewed as an opportunity to clarify information. An example of this can be seen in relation to breast self-examination Spurgeon (2001) argues that physicians should no longer routinely teach women aged 40-69 self-examination of the breast as a screening technique for cancer, because it can do more harm than good. This has produced confusion and anger among women and some disagreement among doctors. Breast Cancer Care (2001), a registered charity in the UK, encourages women to be breast aware as part of their general health routine. Nevertheless, this indicates the mixed messages women receive in relation to one aspect of care. Therefore information needs to be clear and standardised. Mixed messages from varying sources may be the reason for not accepting some information, such as breast awareness, as being useful. However, in planning new services reasons why people do not want information needs to be investigated more thoroughly.

Ellen explained in the focus group

*'The only reason I come back is I **don't** check myself every month now...  
I take the view I found it in the shower last time but I don't physically  
check myself, it's perhaps cavalier but knowing your going to be checked  
once, twice a year, whatever, it puts your mind ..Perhaps gives you a  
false sense of security, but you know you're being officially checked for  
lumps'*

(Ellen).

This can be seen to indicate that attitudes to cancer and strategies for coping with cancer can constrain the wish for information and the effort to obtain it (Leydon et al. 2000). Some patients maintain hope through silence and this influences their desire for information at different times during their illness. The value of hope in the management of chronic illness is well established (Orne 1968). However, Leydon's (2000) small but multi-centered study showed the complexity of the relationship between hope and a patient's desire for information. (Boudioni, Mossman, Jones, McPherson and Leydon 1998). Hope and fear are intertwined and patients oscillate between the desire for more information and the avoidance of new information. Hope might be accomplished and maintained through silence, periods of self-censorship, and not searching for information. These strategies enable patients to circumvent negative information about their illness, which poses a constant threat to hope (Leydon et al. 2000). This intertwining of hope and fear and the inconsistency of information about breast awareness may compound the reasons for Ellen not taking the responsibility to be breast aware.

Information in relation to recurrence was also discussed in the group and the participants felt that the information regarding recurrence and symptoms needed to be carefully delivered, because as Marion stated:

*'I think I would be panicking'.*

(Marion).

and Grace confirmed this:

*'So would I'.*

(Grace).

*Joan spoke about how:*

*'Ever since (the poor examination on the last clinic appointment and a recurrence in the group) this **has** happened to Mary I feel anxious and my last examination wasn't too good.'*

(Joan).

Participants also talked about the need to be able to discuss worries and feelings and they stressed the importance which they would assign to this discussion. Anne spoke eloquently about how:

*'If someone took fifteen minutes to take an interest in you as a person, and how you are doing, I think it would be half the battle is knowing that the person is going to be there to talk to you, the feeling of confidence, that the person will tell you honestly in a proper way what's going on. Really and truly I feel it is part of the therapy'.*

(Anne).

Joan discussed how positively she valued the interaction with her consultant:

*'Maybe I was spoilt by \*\*\*\*\* (consultant) coz of his attendance to you. Examining you and talking to you, he's asking you questions. Over time you know you feel he is actually interested'.*

(Joan).

In discussing support the group mentioned the usefulness of peer support. Anne expressed the view that:

*'It (the clinic) is very public. I didn't go to breast clinic I go to this. I feel in the waiting room you can't have a private conversation. But here in the group it's different; you can talk here about anything. This is monthly whereas the clinic is yearly or three monthly.'*

(Anne).

Another participant discussed how peer support did not necessarily need to be formalized when she related how:

*'As I was leaving the hospital (following treatment) I met a girl and we've kept in touch. So now three of us all around the same time, we all see each other every few weeks. Coz we were the same time it's a bond. We all had chemo. etc. You get paranoid.... It's nice I think you know each other.'*

(Jane).

To concur with this, Pennery et al. (2000) also indicated that 18/24 women felt hurried and that the time given to them was too short in the breast cancer follow-up setting. Leydon et

al. (2000) discusses the frequent references made to the usefulness of the clinic consultation for getting reassurance, which was vital for maintaining hope, and obtaining help in interpreting additional information from independent sources. Nonetheless, patients expressed concern about taking up too much of their doctors' time when other patients were waiting to be seen in the outpatient clinic. These issues appeared more evident among those patients, with close family or friends, who perceived patients without such support as being more needy and deserving of information.

#### **5.1.6 Shared Care.**

There were differences of opinion between GPs around the issue of follow-up being shared between the acute and community services. Three sub themes emerged regarding the willingness of GPs to be involved, the mode of practice and how much this would cost.

Only one GP, very near retirement, felt strongly that breast cancer follow up should take place at the hospital:

*'I feel GP practice have enough to do rather than take on any more. The more you do the more the Government expects you to do. If the hospital wants to change the service, they should fund it. '*

(Dr S).

However, the other GPs were happy to become involved in shared care if it meant that the patients who became unwell received more time in consultation:

*'If a change in service meant the uncomplicated patients were sifted through and perhaps the worried got more time that would be an advantage.'*

(Dr J).

Each of the doctors who were happy to engage in shared care spoke about the need for protocols and quick and easy access into the system, obviously viewing this as a key component of shared care:

*'..referral back would have to be water tight'*

(Dr R).

Some of the GPs felt that shared care could be negotiated in such a way that patients were seen at the hospital for a set number of years and then discharged back to primary care; others discussed shared care being delivered with the help of outreach clinics. They felt this could be a way forward:

*'What do you think of an outreach clinic? Perhaps asking patients where they would like their care is a way forward. An outreach clinic. Perhaps this would help with the time issue too.'*

(Dr A)

and:

*'An outreach clinic could work like skin and eye clinics.'*

(Dr R).

One GP highlighted the role of the specialist nurse as an educator for GP colleagues in primary care:

*'Perhaps if primary care came into play you (specialist nurse) could educate as necessary, do the hand holding...Even combination of care'*

(Dr T).

As can be seen there was evidence of different styles of patient management. Some GPs practice true holistic care and there are others who deal only with the matter of concern before them and example being the GP who said that:

*'If we see a patient who has a cold would we examine them if they came to see us after a breast cancer? I wouldn't'.*

(Dr S).

However, another doctor explained:

*'I have had someone recently who I examined after recent surgery. It makes her feel better'.*

(Dr J).

Another issue that arose during the GP interviews was the financial implications of breast cancer. Some GPs felt that involving primary care would be a cheaper option. However, there were issues of training, additional time and the putting of systems in place to support such a change, which would need additional resources.

The data collected from the GP interviews was not as rich as the focus group and key informant interviews. On reflection the relationship with the researcher and the GPs was not as close as that with the focus group and MDT. This may have hindered the development of diverse conversation or the knowledge of the GPs in cancer follow-up may not have been as expert and the MDT and patient group.

## 5.2 RESULTS OF THE KEY INFORMANT INTERVIEW WITH THE MDT.

Five main themes emerged through data analysis, which illustrates how the multidisciplinary team, working in breast cancer follow-up, experiences and view this episode of care. These themes and the associated sub-themes are presented in Table 2:

**Table 2: Themes and sub-themes from the MDT interviews**

<b>Expertise</b>	<b>Evidence</b>	<b>Psychological aspects</b>	<b>Political issues</b>	<b>Alternative models</b>
Specialist care	Collecting evidence	Support for patients with breast cancer	Rationing	GP managed
Continuity of care	Practice audit	The need for reassurance	Affordability	Hospital managed
Patient/carer education	Breast cancer as a long-term condition	Needs of patients	Patient expectation	Open access

### 5.2.1 Expertise

The breast team, when interviewed, described their views on working in a team and identified some of the benefits which, they felt, were achieved by team working. The importance of specialist care for patients, the issue of continuity and knowledge are paramount in caring for a patient and therefore dovetail together to provide a seamless service. The specialists taking part in the survey considered that the most important developments had been those of breast specialists, multidisciplinary teams and increased public awareness, which was an important element of care, and they felt that these elements should be incorporated in follow-up:

*‘When they (patients) are treated by specialists, follow-up should be by specialists’.*



(Oncologist).

The complexity of managing breast cancer, in a time of rapidly developing treatment modalities, was something that the MDT referred to both explicitly and implicitly. The surgeon described how:

*'If you have pancreatic cancer or stomach or even colorectal cancer, once you have had your adjuvant six months of chemotherapy, there isn't any maintenance treatment or anything like that, so breast is unique'.*

(Surgeon).

Other members of the MDT felt that these treatments would need to be managed by a clinician who understands the speciality and has access to investigations and treatments and has the ability to co-ordinate the pathway. And the surgeon summarised this view by explaining how:

*'If we are recommending treatment which is a benefit to the breast cancer situation, but one of the side-effects is to produce profound osteoporosis, we are actually doing our patients a grave, you know, disadvantage and disservice'.*

(Surgeon).

It appears from the views expressed by other members of the MDT that there are other pressing issues which change throughout the patient pathway and need to be dealt with by the specialist. There are subtle long-term effects of breast cancer therapy such as altered body image, oestrogen deprivation, and fears and uncertainty of recurrence (Rosenzweig 2006). The breast care nurse suggested that:

*'There are physical things certainly and I would say, that are more in the beginning, at the operation, is the very acute time for the patients, the wound and their arm, how this doesn't look right this...'*

(Breast Care Nurse).

She continued to describe changes to the patient. It is thought that, as time advances from the acute phase, more psychological needs are felt by the women.

*'...hot flushes ...as time goes on is it more the psychological starts to build up, have they not had any time to address some of these issues because they are focused on non living for a while and getting through the couple of years of 'My God it hasn't returned!'. Half of these things have been shut away and can manifest later'.*

(Breast Care Nurse).

The seriousness of cancer was also remarked on as was the need for a specialist team to treat this dangerous illness. The oncologist put this point across strongly:

*' I think they've got a potentially lethal disease in which we can interfere with that modality of and we are the right people to do that because we know about the disease, we know what we are doing, we know what is available we are maintaining those patients plugged into all those services'.*

(Oncologist).

MDT members also expressed concern that non-specialists would not be able to manage the complexity of breast cancer follow-up management, and particularly identified that

different types of breast cancer do not show up on mammography. Despite these concerns, recent updated guidelines do not advocate any other mode of imaging (Khatcheressian and Smith 2006). Grunfeld et al. (2006) explains that there is a lack of evidence supporting current practice of mammography surveillance. There is a lack of randomized control trial data, but observational studies suggest that the method of detection (physical examination or mammography), when reported, did not seem to influence survival. However, there are obvious barriers to designing a prospective randomized trial to resolve this anomaly and so mammography remains the only mode of imaging. Interestingly, Montgomery (2007a) investigated whether having a mammogram before 2000 made a difference and it seems to be influential, as stated in chapter three. Before the year 2000 15% of recurrence was detected by mammogram and 46% in routine clinical examination. After the year 2000, 40% of recurrences were mammographically detected and 15% in routine clinical examination. Obviously this needs further research to clarify and assess this data in more detail. The radiographer pointed out that:

*'Yes because the mammogram at the moment (in follow-up) nothing extra is done until something either shows or it doesn't show on their mammogram or in other words they have a lump but hey we can't see it now we go down another road'.*

(Radiographer).

MDT members held differing opinions in relation to continuity of care and hospital based follow-up. Some members of the MDT felt that continuity was good in the hospital team.

*'They all remain under the consultant's umbrella but they see different people depending on need'.*

(Oncologist).

Another interviewee felt that having a relationship with the patient was important in trying to make them patient feel comfortable and enabled her to talk:

*'I think she would be able to open up to speak to you, she may not say something to a junior doctor that may be the essence of what you want to get from her. A few little words and she may feel comfortable to talk to you'.*

(Surgical Ward Nurse).

There were differences between the oncology and surgical MDT members in relation to how well they evaluated continuity of care. The oncology members of the team being more negative about the use of junior doctors and their role in breast cancer follow-up than the surgical team members. Concern was also expressed regarding the examination and the competence of the clinician:

*'But they gonna meet a lot of strange faces and I suppose they won't feel so comfortable and they may doubt the expertise of those people, so they might come away still fretting, did she see that and feel that right and that could be em just familiarity I suppose'.*

(Breast Care Nurse).

Education for patients was perceived by the MDT members as being of equal importance to that of professionals and that it was a part of the specialist team role. This meant that patients and the people caring for them could take some control of the symptoms of the disease, thus enabling them to report concerns earlier. This concurs with Khatcheressian et al. (2006) who state that clinicians should give patients information regarding symptoms of breast cancer recurrence. The radiographer suggested that:

*'Maybe good training with self examination. Because some of these elderly ladies that come, the size of the them (the breast lumps at presentation). They've not been checked for some time em. Maybe education from that point of view. Education of people who actually run some of these homes for the elderly. Some of these come from homes and no one checked have they?'*

(Radiographer).

The role of follow-up was also mentioned and some members of the team questioned whether education was needed to inform patients as to the reason for follow-up and the importance of the holistic nature of cancer treatment:

*' Perhaps a lot of them don't know if they are going to have other tests done... just come back for an outpatient appointment. They come back for follow-up not really sure what's going to happen. This is what you should expect in the coming years rather than coming back every year just for a check up'.*

(Surgical Ward Nurse).

In relation to holistic care and the importance of patients knowing about their disease and when to report changes, education was highlighted as being extremely important.

*'That's right because some patients, particularly old patients, don't realize that there is jigsaw puzzle and everything goes together.*

(Radiographer).

### 5.2.2 Evidence

The MDT members outlined the importance of clinical evidence and how it influences clinical practice and the care that a specialist team provides for patients. The oncologist felt a database would assist with collecting data and felt this could not happen in general practice:

*'So that if Letrozol should be prescribed to all node positive women after five years of Tamoxifen we can immediately start to identify all those patients and we have to write to general practice and say 'by the way we discharged all the patients to you (primary care) can you (primary care) identify, the chances are they will forget about it'.*

(Oncologist).

However, another interviewee felt differently regarding the use of a database. He felt that a good medical record system would be the way forward:

*'My feeling is that data collection is a way of fixing a lack of confidence in medical records. You have a data base which is a duplication of medical records and it is because we do not formally collect data in the medical records and this should be data collection.'*

(Medical Director).

The Early Breast Cancer Trialists' Collaborative Group (2005) published an overview of fifteen years of data regarding breast cancer recurrence and survival rates. From this overview the first years after diagnosis have the highest rate of recurrence this ties in to the new one year reporting following the recent cancer survival data which indicates the mortality from breast cancer is falling but certain PCT areas have worst survival than others. This is thought to be linked with late referral and therefore yearly reporting will highlight late referrals (Mayor 2009). Nonetheless, there seems to be a steady relapse rate through 15 years and beyond. In the case of a woman who has oestrogen positive cancer treated with five years of Tamoxifen, the 15 year probability of death from breast cancer is more than three times as great as the five year probability. These findings have implications with regard to data collection and audit on who has recurrence and who has not. Furthermore, the audit of clinical practice is paramount, especially in light of the current era of endocrine manipulation therapies. The audit of clinical practice, methods of collecting data and the evidence to support practice are a continuum. However, each part has its importance and will be discussed separately.

Treatments of breast cancer have changed over the years as new adjuvant therapies and different treatment options have been introduced, which has obviously influenced the clinical management of patients. Breast cancer is a chronic condition with long term treatments for some patients. Khatcheressian et al. (2006) wonder whether there are data on the new knowledge about adding Letrozole after five years of primary Tamoxifen or switching to Exemestane after two/three years of primary treatment. This new data is complicated and there are concerns regarding how these results will be cascaded to inform clinicians. Khatcheressian et al. (2006) go on to ask how family practitioners will learn and how the patient can keep up to date. The MDT members felt that team working aids the cascading of knowledge and aids audit.

*'We would never know if we discharge all our patients at two years, we just would never know. Because if patients come back with local recurrence we have no idea about how many have got local recurrence, and how many haven't. Em and these issues are very important. What about the axilla? Are we doing an inadequate operation in the axilla or are we doing too much? Do we have a lymphoedema rate of 90% em or are we doing our patients a disservice. These things do not automatically become eh apparent in two years. And what is magical about two years, why not discharge them the minute they've had surgery?'*

(Surgeon).

The issue of how the team would know if patients were discharged and clinical practice was not good was debated, with one MDT member suggesting that:

*If they want their patients to have an optimal long term survival, if they want us to know how well we are doing, that procedures are being successful, it could be that we had done I don't know, a 1000 W.L.E. (wide local excision), it could be at 6 years, eh our local recurrence rate was up to I don't know 50%, our radiologist was wrong, our pathologist were not looking at the right thing, the radiotherapy was missing the target'.*

(Surgeon).

Khatcheressian et al. (2006) also debate how oncology nurses and clinicians will cope if they do not see 'well patients'. Will this contribute to burnout and loss of job satisfaction?

The breast care nurse questioned:



*'How are we going to have any research if they never come back again. We won't know where they've all gone and all the rest of it... so.. You don't know what would be jumping about out there. You might upset some people coming back with wounds who are really terrible disease, unnecessary neglect'.*

(Breast Care Nurse).

The importance of evidence-based follow-up care was stressed by the surgeon who argued that:

*'You are not cured at five years. It is very very clear from up to date evidence that there is a continuing relapse rate, local recurrence, regional recurrence, distant metastases and as follow up has improved. So that would be the reason why I would strongly support, 'em, the continuation follow- up'.*

(Surgeon).

Another MDT member discussed the evidence in relation to breast cancer follow-up and its relevance to new treatments.

*'I think that, that detection of early recurrence does not impact on survival and therefore is not a trigger for follow up is based on old data. It is based on a time when there really wasn't much you could do to salvage. The idea of early recurrent malignancy needs further testing in the era of new treatments and impact on survival such as aromatase inhibitors, such as Herceptin'.*

(Oncologist).

The oncologist has made a valuable point as detection of local recurrences, at an early stage for which curative salvage therapy is available, can be preformed (Dixon et al. 2008). The evidence does not include any prospective data to recommend any particular method of follow-up but in the absence of such data the only available evidence comes from retrospective audits of patterns of relapse and the way these recurrences were detected.

Among the interviewees there was a difference of opinion in relation to the evidence and the benefit of follow-up. It was thought that cancer was extremely emotive and that this, underpinned by historical practice, influenced the way in which follow-up care was delivered:

*'I think there is a danger because cancer a very emotive, very strong and established practices and which when you pin people down medically, have their origins on the old ideas of cancer follow up. The question, the \$64,000 question is where is the evidence that we can detect the asymptomatic and extend life rather than simply treat for longer.....If you basically, if you detect liver metastases by abnormal L.F.T.S (Liver functions tests) you're dealing in weeks. You're basically, the blood test ante-dates the symptoms. So they have their bad news, start their chemotherapy, feel like Hell and actually I don't know to what extent you get a benefit'.*

(Medical Director).

### 5.2.3 Psychological aspects

MDT members recognized that people with cancer suffer significant emotional morbidity and psychological distress and they face physical issues related to their cancer and treatment, end-of-life issues, and survival issues. MDT members felt that follow-up provided support to patients:

*'They probably come back ... maybe it is, a lot of it is psychological, that there's someone telling them everything is ok, they feel better'.*

(Surgical Ward Nurse).

It is recognized that cancer is extremely frightening and patients are cared for in a manner which incorporates psychological support. From the discussions it became apparent that there were no clear systems in place to refer patients for this support:

*'Well I mean, I personally hope that we are looking for, in particularly, in the early part of the follow up depression, anxiety and treatment of symptoms which might be related, but I know that doctors are not always the best people to address these issues and that nurses would pick up more effectively .....*

(Oncologist).

It was suggested that the nursing team appeared to be better at assessing a patient's distress and the breast care nurse suggested that:

*'But that is difference of doctors and nurses. As nurses we home in much more on everything really and you tend to cue better in on the*

*psychological side, we may have already spoken to them about sexual issues and let them know already that there might be a problem and it is introducing that care...*

(Breast Care Nurse).

Several members of the MDT team commented on the lack of formal psychological support for patients if referral is required to a psychological specialist:

*'I would be able to ask (the patient), but the trouble would be to where to feed the person on for expert help, there is just not enough support out there and you are clambering around, I would be stuck, sexual problems.. You be looking up, you do not have a direct pathway in your mind'.*

(Breast Care Nurse).

The medical director did not feel that psychological support was part of clinical care and suggested that support groups could help patients to develop coping strategies which could influence quality of life for these breast cancer survivors. Follow-up was compared to bereavement and continual appointments did assist with patients' rehabilitation. He pointed out that:

*'You are not dealing with that side of the problem and often you know is best dealt with either, either small groups.... or self help or come and meet some people who have been through it. I think it is rather like bereavement... ... If you basically have someone who 'em lose a loved one, basically you go through all the trauma and eventually have the funeral and then someone said well actually it is a requirement that once*

*a year you come and inspect this grave. There is another attitude which says what you really want to do is to allow people to move on'.*

(Medical Director).

At certain points the patient requires more reassurance, which is difficult for the patient and their partner and it can also be difficult for staff that are caring for the patient (Botti, Endacott, Watts Cairns and Lewis 2006). Patients require reassurance because of the uncertainty of their illness. It is the result of side effects in relation to the disease and its treatments, the fear of recurrence and doubts about the effectiveness of the treatments (Wonghongkul, Dechaprom, Pumivchuvate and Losawatkul 2006). Therefore, incorporated in care is a need for hope. Hope, long considered an essential element of life, has been shown to be important among cancer patients in coping, perceived control over the illness, and psychological adjustment to the illness. (Vellone, Rega, Galletti and Cohen 2006).

Long-term breast cancer survivors have a fear of recurrence and of uncertainty about the future. The quality of life's dimensions - physical, psychological, social and spiritual - are continuously affected throughout the patient's life (Ferrell 1996). This appears to be particularly the case during the first three years following diagnosis. The patients have made decisions regarding treatments and coped with the impact of these decisions on their quality of life (Wonghongkul et al. 2006). It is in follow-up that these patients are assessed. Team members described follow-up as providing support for patients following treatments for breast cancer.

*'Part of the security I'm sure is seeing someone professional in a way'.*

(Radiographer).

This was reiterated by the oncologist who believed that the appointments offered psychological support to patients:

*'I think, even though they do not come all that often, I think it is a little plank of psychological support'.*

(Oncologist).

There were also comments on how the diagnosis of cancer and the fear it brings is difficult to come to terms with and how the clinic appointments help to make the patients feel more confident:

*'Reassurance, purely reassurance. It's that comfort zone, they have been with us such a long time; they feel confident in the team looking after them. That's really it; they might only be there a couple of minutes and for some reason sit for hours and they feel better going out the door and sometimes very little done. I do think it is that fear thing'.*

(Breast Care Nurse).

In the specialist and research oncology setting, studies have consistently found that nurse-led clinics are safe, effective, acceptable, and cost effective (Moore et al. 2002) (Cox et al. 2006). It has been common practice for doctors to practice follow-up but it was felt that different roles for nurses were being accepted by patients.

*'Although some of them like the white coat. .... But I think in 2005 more and more people are prepared to accept a nurse as a specialist... ... (page eight)... there never will be enough time but I think that generally speaking em a combination of the Nurse Practitioner, who is hopefully*

*more attuned and more likely to be on the same wave length tuning in on that right wave length for the patient.*

(Surgeon).

This interviewee explains that he felt that nurses are more in tune with patients' needs. However, Middleton, McKinley and Gillies (2006) recently wrote in the BMJ that the consultation between the doctor and the patient is the core activity in clinical practice. But, in line with the interviewee, many patients report that they have been unable to discuss their concerns with their doctors. It was thought that this situation could be improved by education to enhance communication skills. The surgeon also highlighted the difficulties of clarifying the needs of the patients and the needs of the doctor and suggests how education can assist this.

*'Now I went to this communications course and I was looking at what we did at the end of the course, we wrote down on a piece of paper (looking for the paper) what we got out of that. **The number one** (voice lifted) issue that I got out of there was we think we know what the agenda is as clinicians... we may think that the critical issue here is deciding whether to have a mastectomy or a lumpectomy but what is actually bothering the patient, is whether they should tell their mother or not'.*

(Surgeon).

Moreover, when the patient need has been established it is difficult, for various reasons, for the patient to open up to the person caring for her. The breast care nurse identified that:

*'Ahh (big sigh) I suppose the trouble it is the environment too, to be honest horrible rooms here and undressed and are you really going to be talking about sex life, breast are bared, there is probably not even the*

*right environment to come out with half these things. I don't know, even to the fact that some doctors, I have had some patients say I didn't want to ask xxxxxxxx (name of doctor) about my discharge because they felt a bit awkward em... asking me out in the thing so ... (clinic waiting area).*

(Breast Care Nurse).

She goes on to explain the importance of feeling comfortable with the person and therefore of being ready for dialogue to take place:

*'... There is a little bit of that maybe as well. Feeling comfortable with right person so it would have to be the perfect environment and not so rushed but this is the stuff of magic'.*

(Breast Care Nurse).

Reference was made to the possibility that by introducing follow-up we condition patients to expect this service and to expect that there may be problems/recurrence in the future:

*'Actually conditioned them to expect a problem... If you basically say to them right at the outset here is your plan, we have shown that scientifically there could be some value in you having some mammography on your other breast every eh three years you might develop another cancer and explaining that very delicately...'*

(Medical Director).

Frankel and Quill (2005) discuss the importance of doctors being self aware which then enables them to approach and negotiate with the patient. They discuss the use of a



biopsychosocial approach which selects aspects of care that are important to the patient. Many patients do not want to establish relationships with the clinical teams and do not want to be involved in the decision making and others want a combination of approaches to the making of decisions. Therefore, understanding the patients' expectations and the issues of the emotional burden is paramount in developing an efficient framework for care. To use a full emotional framework in caring for each and every patient would be overwhelming. Therefore, clinical empathy is suggested. The clinical teams are in tune with the patients' and physicians' own emotional stress and they develop care according to the patient's need (Larson et al. 2005).

#### **5.2.4 Political issues**

The thorny issues of rationing of services were something that was referred to by some of the MDT members. The radiographer suggested that:

*'No government is brave enough to put up taxes to cover all of these.  
Which is all it needs in my personal opinion? Up the tax marginally and  
let us all have it without any worries'.*

(Radiographer).

She went on to point out that financing was difficult and that specialties were competing with each other to gain access to funding. The increase in work load with new imaging and higher expectations of patients is putting pressure on resources:

*'... with the number of women coming through, you are adding on all the  
time, aren't you, you aren't getting rid of the same number as are coming  
on so it is always tsh tsh (arms widening ) expanding and one day it will  
go pop'!*

(Radiographer).

Another interviewee highlighted the difficulties of new cancer drugs and other competing services:

*'Well listen, it is what I said to the same lady last night, she was talking about Herceptin and it should be available and I said to her look I said if the same pot is available and we give PCT £100,000 (hundred thousand) for Herceptin treatment it means there is £100,000 less for something else and who's to say whether we should provide an extra five intensive care unit beds for children or hip replacements for very seriously in pain or em renal transplant or or so its not so straight forward.*

(Surgeon).

Other interviewees highlighted the point that services may have to change to redirect monies, affordability and accommodate the new work load:

*'The premise would be that it is within the gift, as it were, of the breast care providers to say we think we can spend our money better. We don't want to lose the investment to breast care, we want to redirect it. Instead of bringing people up to the outpatients department we want to have people who can make the phone calls, be on duty whether they are able to respond to the phone or at least leave a message and someone will get back to you. Em and you basically say as a result of that do away with it'.*

(Medical Director).

Concerns were voiced regarding the volume of new patients and the number of patients in follow-up for long periods of time:

*'For the people coming back for at least 20 years, just for yearly check up just to say hello and everything is fine and on your way. You know shouldn't we make room for the new patients rather than they know the system at this stage, they know if anything is wrong they can just phone in, yet they like that yearly visit'.*

(Surgical Ward Nurse).

The perspective of these MDT members reflect that of Camidge et al. (2005) who suggest that decisions not to fund some treatments has become a fact of life in our health care system. Economic assessments are made and these assessments underpin rationing decisions in relation to health care, although it remains unclear whether the public's values are incorporated into these cost effective analyses. There is a need for more information and a better way of analysing the data and the debate is often focused around specific drugs or procedures and how these are funded (Klein 2005).

One interviewee held very strong views as to whether the health service could afford cancer follow-up in the light of the current financial climate

*'But in essence I think the modern health service, for better or worse, has introduced a clearly financial model which basically requires doctors/health care professionals to give an accounting to a limited resource. So when ever you're spending that money, you must be in a position to show why your spending that money gave better health benefit to the community than someone else, given that there will never be enough to satisfy every aspiration'.*

(Medical Director).

He went on to further clarify his beliefs

*'As a result if we diverted all the money that we currently consume, doing fruitless follow up into recruiting a small army of breast care professionals, could we not do a deal with the health economy. If we halved our costs could we not reinvest it in where we need it? And actually presently our costs of running our breast care service is a billion pounds or whatever... cumulatively of that £250,000 are enormous follow up practice - secretarial work, the note keeping that goes with it, investigations. We have actually looked at this. We think if we spent £100,000 in a much more focused way we would have happier bunnies'.*

(Medical Director).

Another aspect of the political aspects of care that emerged during the interviews was the issue of changing patient expectations. Once breast cancer has been diagnosed, it has been traditional to provide a breast cancer follow-up service for all patients. This was debated by many of the interviewees, with the surgical ward nurse stating that:

*'and others (patients) feel - I have been called back so I should show up and attend'.*

(Surgical Ward Nurse).

The medical director suggested that:

*'I do believe we train our patients to expect what we give them. I believe there is a slightly Pavlovian response because at a very early stage, with the best of intentions, we say to patients you have had your operation, now everything is clear but don't worry we are going to keep an eye on you...'*

(Medical Director).

However, another member of the MDT felt strongly that:

*'I am used to this system and we are brained washed anyway. Do you think? I don't know, it may work well (changing follow-up) and if I come back ten years later it might be the normal and no one blinks an eye about it. I just think there are so many treatments, so many breast cancer treatments, but it is getting so complicated, side effects and how long are these things lasting, the recurrences and keeping up with all the research, how are we going to have any research if they never come back again. We won't know where they've all gone and all the rest of it... so ...'*

(Breast Care Nurse).

The surgeon drew attention to the fact that the breast screening programme screens women who have not had cancer or a family history of breast cancer. Even in light of recent media coverage of the over diagnosis in the breast screening programme, clinicians in the MDT felt it important to investigate the subtle changes which may occur on the mammogram of a patient who has had breast cancer.

*'If the patient has had a mammogram and m.c.c.(micro calcification - a change seen on a mammogram) is beginning to develop leading on to pre-cancer and possibly breast cancer. If we screen normal patients we should screen patients who have had cancer'.*

(Surgeon).

The difficulties of not working in an ideal world were summarized by the medical director:

*‘So whatever I say does not mean that we are in an ideal world, with unlimited funding. One could not satisfy every desirable endpoint of satisfying the every wish and preference of every individual patient’.*

(Medical Director).

### **5.2.5 Alternative modes of follow-up**

There is a variety of models that could and have informed the provision of breast cancer follow-up services although it was felt by some MDT members that GPs may not have the specialist knowledge to provide specialist services.

*‘The only thing is their case load would be indebted to the hilt, I am sure they would not want all that. They do not want the responsibility of it all coz they don’t know enough all the long term drugs and they are not up to date in each specific thing... Oh they would only know little smidginens wouldn’t they?..... Then I suppose we would have to have a massive GP educational programme then. We’d be going out doing more of that wouldn’t we?’*

(Breast Care Nurse).

This role for a breast care nurse was suggested by the GPs in their interview. Dr T felt the specialist nurse could do the ‘hand holding’ even a combination of care. Grunfeld et al (2006), in results of an economic review, felt that GP follow-up was safe in relation to recurrence detection and that it did not have an adverse effect on quality of life. However, the interviewees in this study felt that GPs locally would not want to undertake this extra work or that they would not have the clinical expertise to do so.

*'Em If you talk to the average GP there are very very few of them who either have the training, experience, knowledge or interest and indeed in the new contract that they have they, are really hard pressed to do the other stuff that they already have to do.*

(Oncologist).

However, from the interviews some GPs were interested in shared care. They felt with an educational programme, some additional resources and protocols of referral back to the hospital, it could be done. This vision of care was also highlighted by the surgical ward nurse that follow-up should relocate to GP practice but remain with the specialist team.

*'They could be seen at their GPs probably by a breast specialist One day someone to go to the GP clinic have a room and have all the ladies there. To be seen quickly so you are not going to have all the new cancers there sitting. You are going to have everyone in the same kinda boat just for the follow up. Not to be told any bad news as such, just to have their follow-ups done that way. Taking them out of the hospital setting where they have probably been diagnosed and frightened. Take it away somewhere else'.*

(Surgical Ward Nurse).

There was some support for a community-based model it was felt that it could work but that it would need a structure and underpinning for the future. The oncologist suggested that:

*'I think it is starting and what I am talking about, so I can foresee a situation which you could relocate the follow-up location somewhere else but you still need specialists, you need people who are trained and experienced and know why they are doing what they are doing, go to meetings and lectures and so on CP(clinical practice)..... so should it be in hospital? Well I think we have the set up for it, do we want to create new environments is a separate question which needs developing services further beyond where we are now'.*

(Oncologist).

Respondents in this study felt, in the main, for the present, hospital based breast cancer follow-up services were better, but that nurses could assume this role and develop the service.

*'So I think that this is something that I am very very very keen on, em, and I think that the combination of the two em, of formal Nurse practitioner clinics, where everything is very, very, well processed. You go to definite protocols but you have ability to sit and patients have the opportunity and that the opportunity to speak to someone who is an expert and on the other hand is someone that they know, that someone they feel relaxed with'.*

(Surgeon).

Although a substantial minority of patients reported that they experienced pre-visit anxiety, most of them felt that this disadvantage was compensated for by reassuring results, and believed that investigations did not have a significantly negative impact on their quality of life. Respondents valued hospital follow-up, and half of them would reject complete



discharge or alternative forms of follow-up. These findings demonstrate that patients have a different perception of the risk of recurrence to the perception of clinicians who would consider the survival prospects for most patients to be more or less unaffected by follow-up interventions. Attempted modifications to follow-up policies should be introduced with caution and should take account of the patient's understanding of medical rationale. The findings also raise questions about risk to communication with patients. Cox et al. (2006) discusses nurse-led lung follow-up as being a hospital based service led by nurses with specialist knowledge to meet the psychological needs of patients in the follow-up phase. This was a view supported by the oncologist:

*' So I have no doubt these are the right kind of people, nurses, specially trained nurses, breast nurses trained in follow-up, got no problem with that either, but we already discussed our own set up that the nurses want to follow, a certain sub group of relatively low risk patients and we would want to reserve the high risk patients by the medical team in the same environment. If I want an easy exchange, if the nurse is worried about a patient, she would need immediate access and the patient is seamlessly transferred into further investigations instantly'.*

(Oncologist).

However, there were concerns regarding this role expansion and its impact on nursing, and the breast care nurse presented these as:

*'Nurses could do the follow-up but it is a way of getting through lists and meeting their targets which is an agenda for the trust. How much we are an hour and the cost of a doctor an hour. We are cheaper labour, are we being slightly exploited, this great influx of nurse practitioners, nice*

*esteem of nurse practitioner clinics but are we being brain-washed and exploited ... We do not seem very backed up by very strong legal measures. Sometimes we are failing around a bit'.*

(Breast Care Nurse).

An 'Open access' model of follow-up was suggested by the surgeon, although he expressed concerns regarding the coordinating of test results.

*'From our point of view mammographic surveillance, tumour markers em etc and of course the is the old argument while best to discharge patients to the GP and if there is a problem, let them come back and we will have more room for them to come back. More of an open access clinic but then who runs the mammographic surveillance set-up? Em who runs the the tumour marker surveillance?'*

(Surgeon).

One solution to this was the suggestion to involve the breast care nurse in the coordinating of the results and to spend the monies differently.

*'We would much rather you to have open access to advice and all that will happen is that you will automatically be sent some blood tests, some x-rays, you don't need to worry about it really, we are collecting information but I think if you condition people it would be vastly better there is someone that every now and again perhaps you set up the BCN would ring up and say - Hi Mrs Jones haven't heard from you in a long time. How are you getting on? Well, no worries' .*

(Medical Director).

It was also suggested that the patient's experience should be considered and that there should not be the same service for everyone.

*'Yeah someone still remembers them and taking their plight into consideration and what they have gone through'.*

(Surgical Ward Nurse).

It was felt that by changing some aspects of follow-up would leave more time for the psychological aspects of care:

*'They get quickly examined and I am sure half the things picked up, they would phone and tell us about anyway beforehand..... And the mammogram and coming back for the result, well that could be told really unless there was something different. Well... I don't think clinically there is a lot of benefit apart (big sigh...UH ) apart from the more nursing aspects because they could then talk if they had time, you see the doctors do not give them time they are just slotted in and out but if they were asked more questions about how are you coping with the drugs. The Tamoxifen: any side effects? Just even psychological things that we don't even go into, because of that short time... That's what we are not touching on and perhaps they may come away more beneficial from that in depth questioning'.*

(Breast Care Nurse).

### **5.3 SUMMARY**

Themes from the focus group, GP and MDT interviews interestingly concurred with each other. The need for reassurance that the cancer had been treated and that the participants were well was discussed by the focus group, the MDT and the GPs. The official check by the clinicians validated the patient's wellness but to ensure this the issues of continuity was an important aspect to care for all interviewed. The need for a clinical examination was important and the need for consistency of this examination was paramount. The doctor/patient relationship instilled confidence in their management rather than continual questions about their previous cancer treatments. During a period of uncertainty following a cancer diagnosis and treatment, confidence in the clinical team is overriding principle. This aspect to management would be explored in the patient questionnaire.

The vulnerability of the women was discussed in the patient focus group. Due to the sexual nature of the breast examination, the fear of a recurrence and the importance of recurrence being detected at the examination, this caused the participants a lot of anxiety. Moreover, communication between the doctor and the patient in relation to the style of communication, the up to date information about treatments, health education and the opportunity for women to ask questions was important in the follow-up setting. These themes would be developed further in the patient questionnaire.

GPs also discussed a model of shared care between the hospital and primary care. They described aspects of management which would need to be in place to ensure care was safe. These elements will be further investigated both in the patient questionnaire and the GP questionnaires.

The MDT interviews also agreed with the psychological aspects of care, the importance of continuity and reassurance. Information was also discussed in light of extended adjuvant therapies and the education of patients and their carers with the importance of reporting abnormalities and the compliance of medication, this is an important element to care. There was dispute between hospital clinicians about clinical expertise and transferring care to the community services. This dispute may also relate to underlying issues of power but these aspects of breast cancer follow-up management were raised by the GPs in their interviews and are a significant element of development to a new model of follow-up care. However, there was agreement for the relocation of follow-up into primary care but the team remain to manage the care with the possibility of a nurse from the MDT to provide the expertise.

Group/peer support and nurse led cancer follow-up maybe a mechanism to develop services if appropriately facilitated and education to underpin clinical practice and an issue of discussion in a new model of care. As the NHS stands at present it was discussed that follow-up maybe an expensive service. However, if breast cancer practices were evaluated and the potential and feasibility of developing a new model of breast cancer follow-up was developed, monies may be freed to be the catalyst to change and develop a new service for the local population. There is a good degree of consistency and similar themes emerging from the data. Psychological support is an important aspect to care and there appears to be a consensus for a different approach to follow-up with robust protocols of referral back to the acute trust if needed. These key elements will be further investigated with the questionnaires to the GPs and breast cancer patients.

## **CHAPTER SIX – SURVEY FINDINGS**

### **6.0 THE PATIENT SURVEY**

The patients in the research project had received their treatment for breast cancer and were in the follow-up stage of their management. Over a six month period clinic lists were ascertained and patients highlighted, with medical notes, who met the research criteria. The women were contacted in writing and requested to attend the clinic ten minutes before their appointment and information regarding the study was sent to their home address. The issue of consent was discussed in the letter of information but the consent forms were completed at the clinic. The questionnaires were completed in the clinic setting with the assistance of University staff over a six month period. Prior to the interview the treatment and histological outcomes were documented by one of the nursing team, who was not involved with the research, and they were clarified with the patient during the interview. Names were documented. In total 111 women took part in the survey. All women who were invited took part, representing a response rate of 100 percent. Four in five new cases are diagnosed in women aged 50 and over, with the peak in the fifty to sixty-four age group (Office for National Statistics 2004). This is borne out in the small sample in this study since the highest number of patients presenting with symptoms are in the screening age group (See figure Three). However, it was not investigated by using the medical notes where the patients had been referred by either their GP or local Breast Screening Unit.

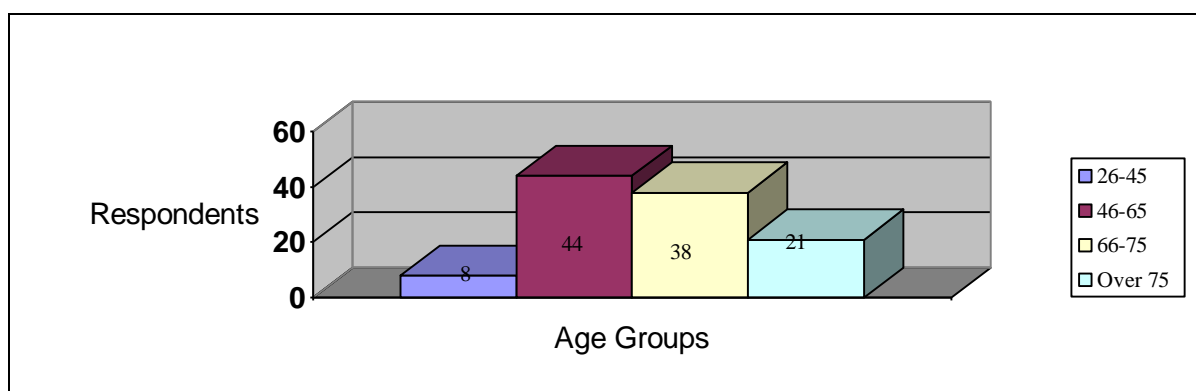
### **6.1 SAMPLE DEMOGRAPHICS**

#### **6.1.1 Age of the respondents.**

The ages of the respondents were ranging from 26 plus to 75. This allowed the study to have the benefit of experience from different treatments and the effects of age and socioeconomic factors. The National Breast Screening Programme screens all women

between the ages of 50 and 70, as it is well documented that the incidence of breast cancer increases with age.

**Figure 3 – Respondents by age**



### 6.1.2 Ethnicity

Ninety (81.1%) respondents identified themselves as British and minority groups are illustrated in Table 3. This is in line with the 2001 census findings for the local population (Office for National Statistics [www.statistics.gov.uk/census2001](http://www.statistics.gov.uk/census2001)).

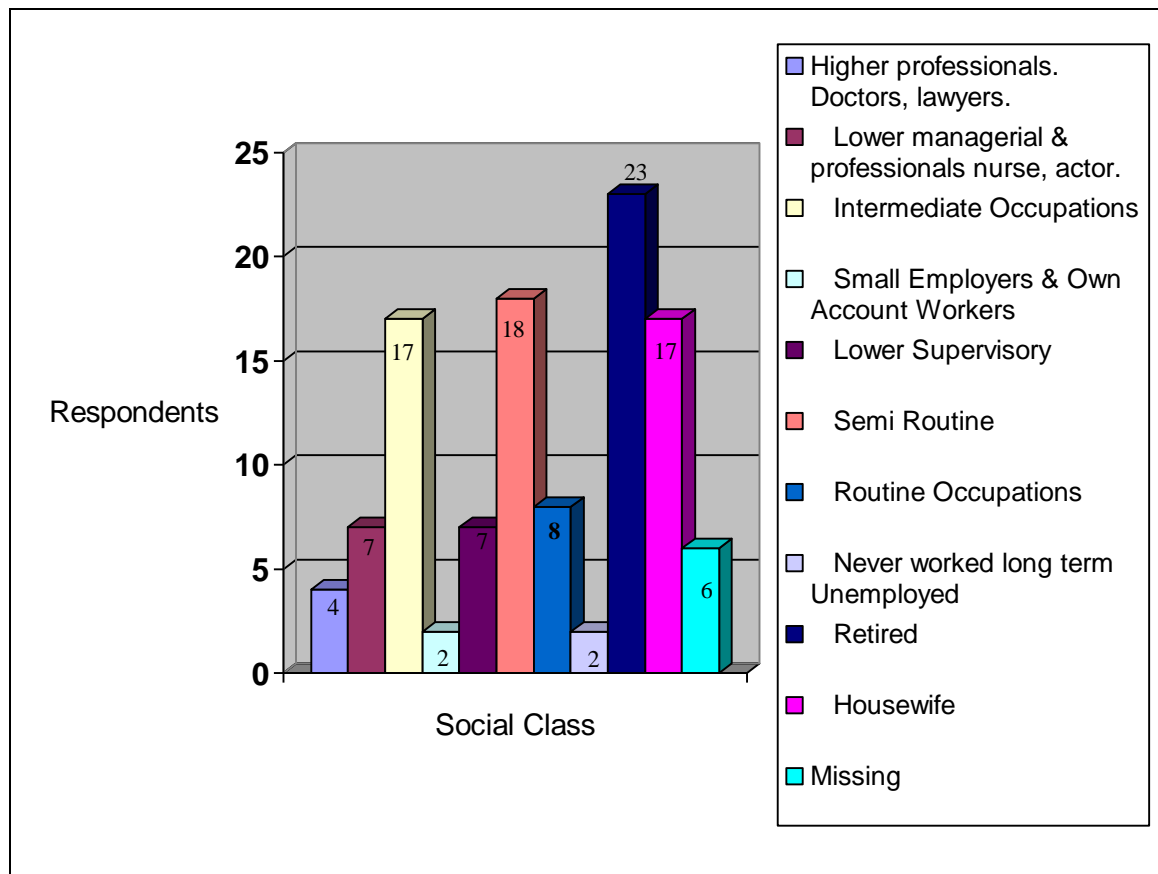
**Table 3 - Respondents by ethnic group**

Ethnic Group	Number	Percentage
White British	90	81.0%
Irish	10	9.0%
Other	7	6.3%
Cypriot	3	2.7%
Other Asian	1	0.9%
Black Caribbean	0	0
Indian	0	0
Black African	0	0
Other Black	0	0
Bangladeshi	0	0
Chinese	0	0
Pakistani	0	0

### 6.1.3 Socio-economic status

All socio-economic groups were represented, with the largest group drawn from the retired class (Figure 4). This is reflective of the socio-economic population of the local area in which the case study was located Office for National Statistics. ([www.statistics.gov.uk/census2001](http://www.statistics.gov.uk/census2001)).

**Figure 4 - Social Class of the respondents**

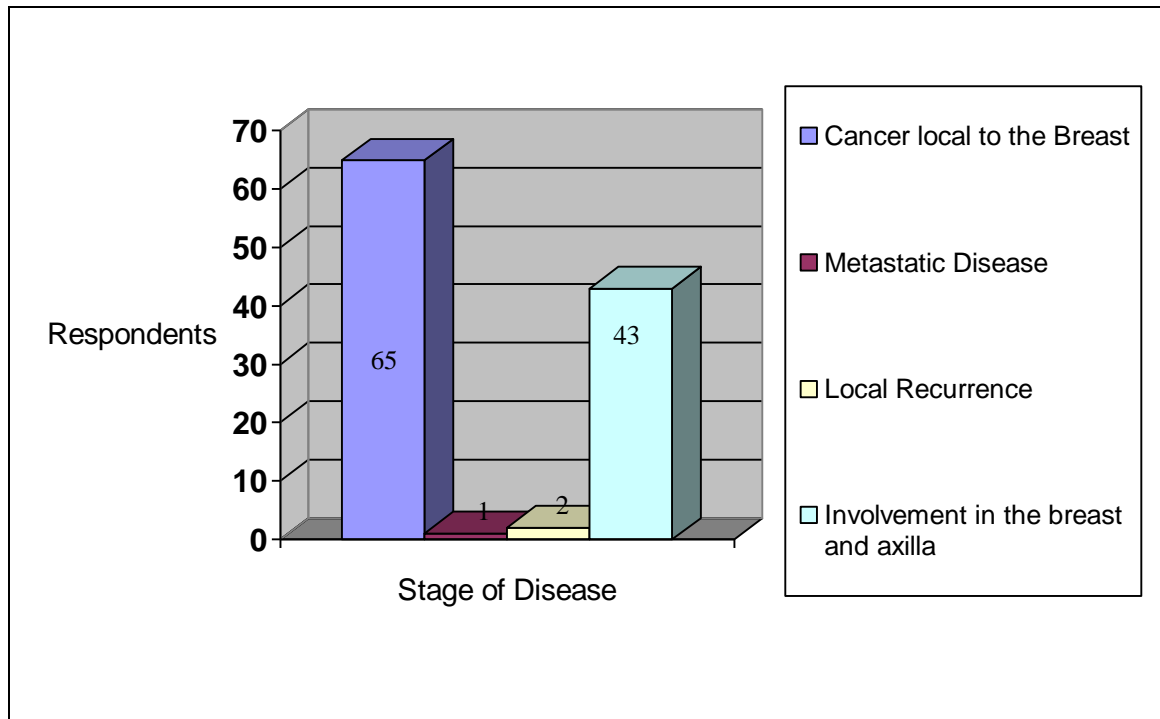


### 6.1.4 Disease staging

From the 111 respondents 65 were found to have disease, local to the breast, and 43 had disease involving the axilla (Figure 5). This reflects a proportion of patients with breast cancer under the care of the breast unit.



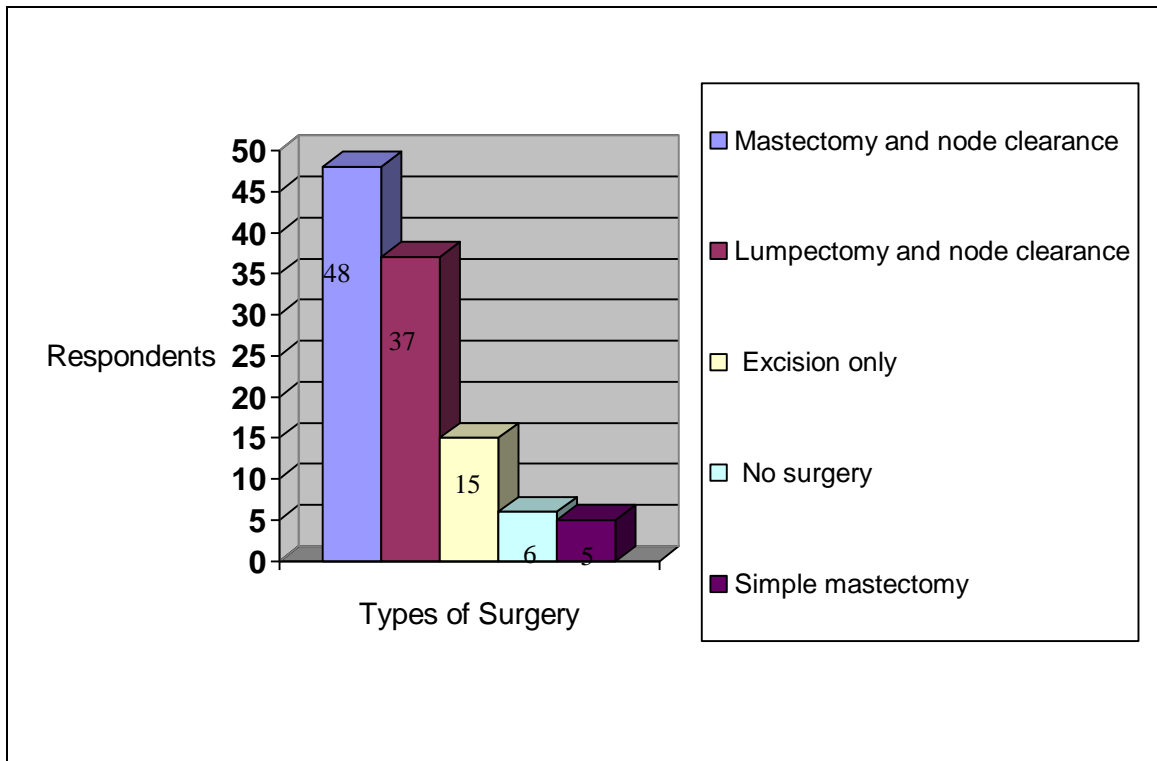
**Figure 5 - Stage of disease**



#### **6.1.5 Treatment**

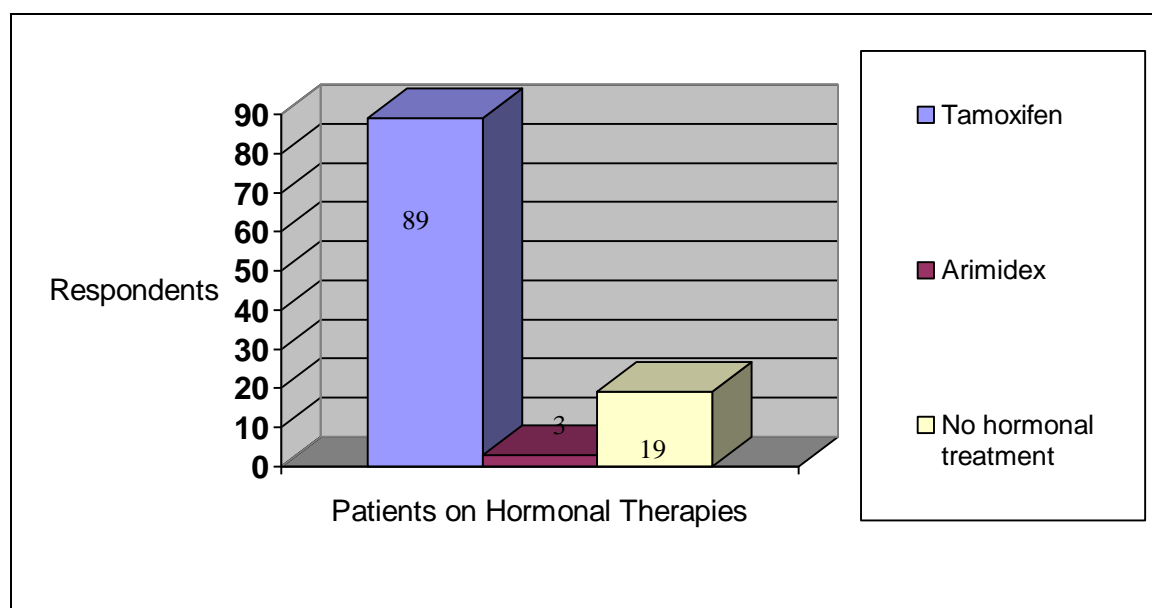
Breast cancer is now managed by giving patients a choice in relation to treatment options (Sainio and Lauri 2003). It is now deemed clinically safe to offer women breast conserving surgery rather than mastectomy. Even with this development of breast conserving surgery and although the data showed that the disease was confined to the axilla, respondents underwent mastectomy as the first line of treatment (Figure 6). From the sample, 3 (2.7%) respondents had received neo-adjuvant chemotherapy and 2 went on to have a mastectomy.

**Figure 6 - Types of Surgery**



Following surgery, 78 (70.3%) of the respondents went on to receive adjuvant radiotherapy and 50 (54.1%) received chemotherapy at their local cancer centre. This is in line with treatment guidelines in the local cancer network. Eighty-nine (80.2%) respondents were taking Tamoxifen tablets, once the chemotherapy and radiotherapy had been completed, and 3 (2.7%) were taking Arimidex tablets. It appears that, with these adjuvant therapies, the survival of breast cancer patients has improved and this study was prior to the explosion of the new hormonal manipulation medications and new monoclonal antibodies (Figure 7).

**Figure 7 - Respondents receiving hormonal therapies**



The sample of patients surveyed in this study reflected the breast cancer population in the study site at the time it was carried out. The caseload has now changed with the implementation of the Cancer Plan initiatives (2000) resulting in an increasingly younger patient population, something that will be discussed later.

## **6.2 EXPERIENCE OF CURRENT SERVICE.**

The respondents were asked who had examined them last in the clinic and what their expectations were of breast cancer follow-up clinics. The breast clinics, where follow-up was researched, organised the service randomly so that some patients received follow-up from any doctor within the breast team and some patients received follow-up from the original surgical consultant and the original specialist nurse together. Eighty two (73.9%) of them saw a doctor from the surgical team and 29 (26.1%) of them saw the consultant and Clinical Nurse Specialist (CNS) together (Table 4).

**Table 4 - Patient expectations of breast cancer follow-up.**

<b>Expectations</b>	<b>Number</b>	<b>Percentage</b>
For checks to be performed	85	76.6%
For reassurance	41	36.9%
To report problems	18	16.2%
To be listened to	11	9.9%
To see the doctor	7	6.3%
To gain information	6	5.4%
To be looked after in the future	4	3.6%
To receive results	2	1.8%
To find follow-up to be a waste of time	2	1.8%
To be cared for	1	0.9%

From Table 4, it can be seen that respondents expected to receive treatments and investigations and to obtain information and reassurance from attending follow-up clinics. These responses are in line with the literature regarding the support which patients require during the follow-up period (Fallowfield et al. 1994), (Clark, Wray and Ashton 2001). The uncertainties and fears, experienced by a person who has been diagnosed with breast cancer, are likely to result in a more pronounced need for social support (Allen 2002). The themes, emanating from the table, represent the cycle of emotions associated with the follow-up experience. The respondents wish to know that they are well and free of disease, but also need to feel cared for and supported by the medical staff.

The respondents were asked for their opinions as to how the breast clinic was organized and whether, in certain areas, it met their needs. The breast clinic was an extremely busy clinic and concerns around privacy and dignity were highlighted within the focus group. From the 111 respondents, 106 (95.5%) felt that privacy and dignity was met. (Table 5).

**Table 5 - Dignity and privacy needs**

Scored	Number	Percentage
Fully met	106	95.5%
Partially met	4	3.6%
Not met	1	0.9%

As the service is currently organised, 91 respondents were asked about the information which they receive in clinic and 91 (82%) felt that it fully met their needs. However, 16 (14.4%) stated that it only partially met their needs, as the service is currently organized (Table 6).

**Table 6 – Information needs**

Scored	Number	Percentage
Fully met	91	82.0%
Partially met	16	14.4%
Not met	2	1.8%

As the service is organised, the respondents were asked if they had enough time in the consultation. Because the clinic is extremely busy and frequently overruns its schedules, it was expected that time would be an issue for the patients. However, 98 (88.3%) of respondents felt that it fully met their needs. Ninety (81.1%) of them felt that time expectations were fully met but 17 (15.3%) of them stated that their expectations regarding time were only partially met (Table 7).

**Table 7 - Adequacy of time for consultation**

Scored	Number	Percentage
Fully met	90	81.0%
Partially met	17	15.3%
Not met	2	1.8%

Eighty-seven (78.4%) respondents felt that their expectations of being seen as a person and not just as a patient were fully met as the service was currently organised. Unfortunately 10 (9.0%) of them felt that their expectations of being seen as a person were not met as the service is currently organized. (Table 8).

**Table 8 – Person not patient**

Scored	Number	Percentage
Fully met	87	78.4%
Partially met	12	10.8%
Not met	10	9.0%

There is no statistical significant association between demographic variables, disease stage or treatment and the responses relating to patient expectations of the current service.

### **6.3 VIEWS OF THE CURRENT SERVICE.**

The patients in the clinic were asked three main questions about their expectations in attending the breast cancer follow-up clinics, how important these expectations were to them and what they saw as being the benefits of attending breast cancer follow-up clinics. Forty two (37.8%) of the women felt that one of the purposes of follow-up was to have problems dealt with in the clinic. Seven (6.3%) of them felt that treatment was a purpose of the clinic appointment and 10 (9.0%) of them thought that receiving up-to-date information was a reason to attend breast cancer follow-up clinics. Only 2 (1.8%) of the patients scored 'healing' as a purpose of follow-up and only 1 (0.9%) patient wrote that seeing the doctor was a reason for breast cancer follow-up attendance, with one (0.9%) patient highlighting continuity as being the purpose of clinic attendance. Seventy seven (69.3%) of the respondents felt that to gain reassurance was a reason for attending breast cancer follow-up clinics (Table 9).

**Table 9 - The purpose of breast cancer follow-up clinics.**

<b>Purpose of follow-up clinics</b>	<b>Number</b>	<b>Percentage</b>
Reassurance	77	69.3%
To have problems dealt with	42	37.8%
To receive up-to-date information	10	9.0%
To receive treatment	7	6.3%
Healing	2	1.8%
To see the doctor	1	0.9%
Continuity	1	0.9%

As the service is currently organised, the respondents were asked how important they considered some aspects of breast cancer follow-up to be. Ninety three (83.7%) of them stated that maintaining privacy and dignity was very important and 14 (12.6%) of them scored this aspect as important (Table 10).

**Table 10 - The importance of privacy and dignity**

<b>Scored</b>	<b>Number</b>	<b>Percentage</b>
Very Important	93	83.7%
Important	14	12.6%
Not Important	2	1.8%
Missing	2	1.8%

The gaining of information was scored as 'very important' by 97 (87.3%) of respondents. Eleven (9.9%) of the patients felt that it was 'important' to receive information and no one scored it as 'not important' (Table 11)

**Table 11 - The importance of obtaining information.**

<b>Scored</b>	<b>Number</b>	<b>Percentage</b>
Very Important	97	87.3%
Important	11	9.9%
Not Important	0	0
Missing	3	2.7%

Ninety six (86.4%) women scored 'being listened to' as being very important to them in breast cancer follow-up clinics. Eleven (9.9%) of them scored this aspect as important and none of the sample felt that this was not an important aspect of cancer care (Table 12).

**Table 12 - The importance of 'being listened to'**

Scored	Number	Percentage
Very Important	96	86.4%
Important	11	9.9%
Not Important	0	0
Missing	4	3.6%

The importance of the availability of adequate time in clinics was rated. Ninety (81.0%) of the women considered this as a 'very important' aspect and 19 (17.1%) of them scored the time aspect as 'important'. As before, no one scored it as 'not important' (Table 13).

**Table 13 - The importance of time availability**

Scored	Number	Percentage
Very Important	90	81%
Important	19	17%
Not Important	0	0
Missing	2	1.8%

Finally 'being seen as person and not just as a patient' was an important aspect of breast cancer follow-up. Ninety one (81.9%) of the respondents considered this aspect as 'very important'. Fourteen (12.6%) of them felt it was important and 3 (2.7%) of them were missing. Three (2.7%) of them considered it as not being an important aspect to care (Table 14).

**Table 14 - The importance of being seen as a person**

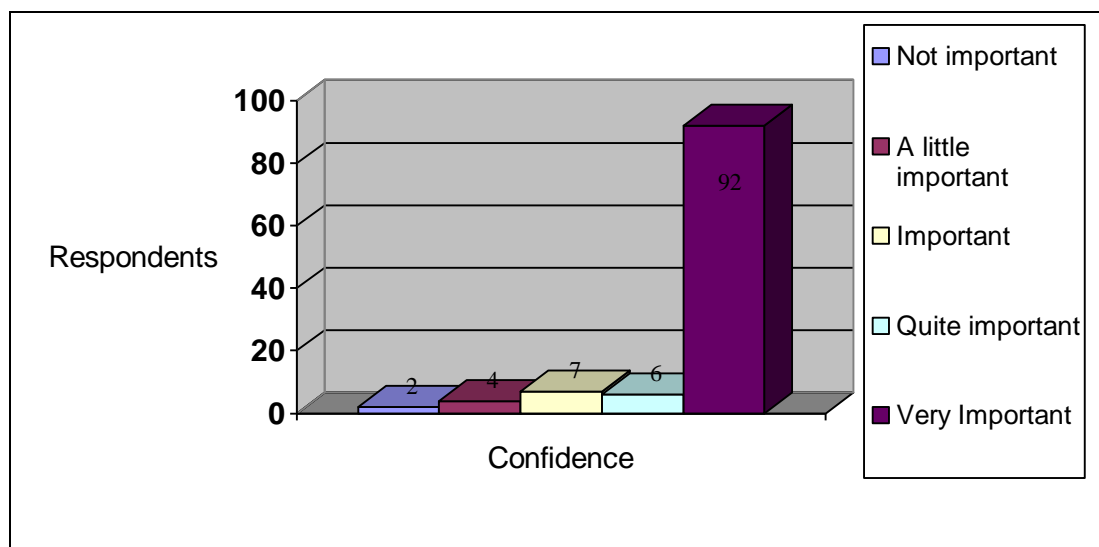
Scored	Number	Percentage
Very Important	91	81.9%
Important	14	12.6%
Not Important	3	2.7
Missing	3	2.7%



#### 6.4 THE BENEFITS OF BREAST CANCER FOLLOW-UP CLINICS FOR THE PATIENTS.

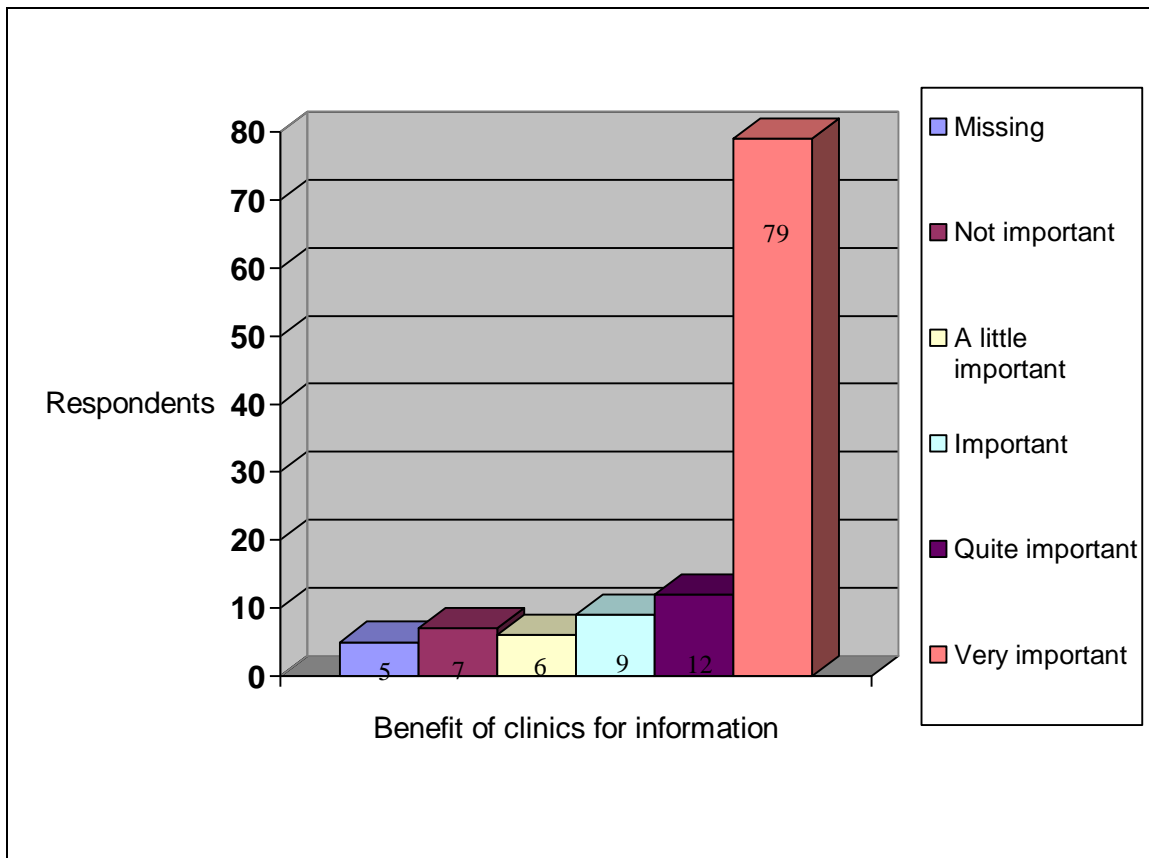
Ninety two (82.9%) of the respondents felt that the benefit of attending breast cancer follow-up clinics was a feeling of confidence in their progress (Figure 8). A reassurance that the disease had not recurred was an important aspect of the care that the patients received in clinic and they felt that this reassurance should be an integral part of follow-up treatment. This approach gave the women confidence and hope which is an important factor in survivorship (Leydon et al. 2000).

**Figure 8 – Benefits for confidence**



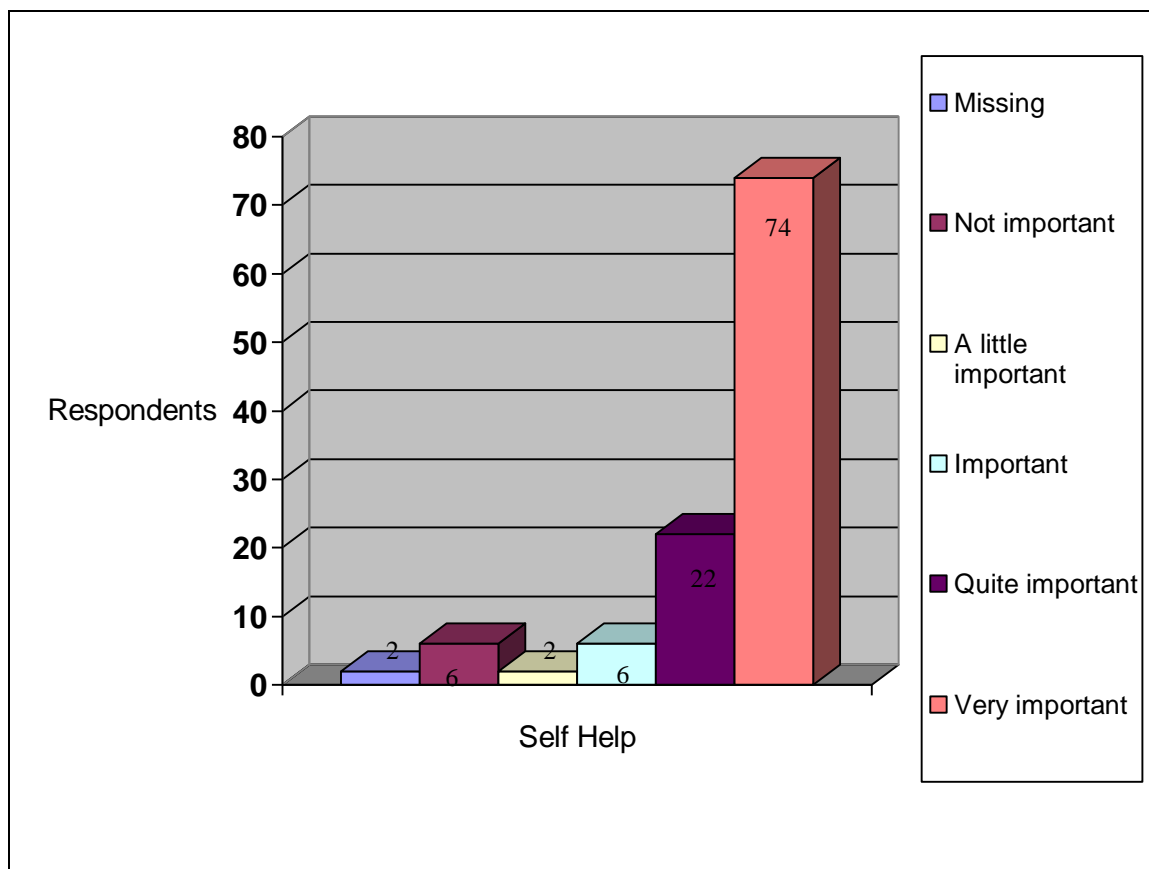
Seventy nine (71.2%) of the respondents stated that the gaining of information regarding the disease was very important. When diagnosed, patients require a lot of information regarding cancer treatments and investigations and also require information in the follow-up setting.

**Figure 9 - Benefits for information about disease**



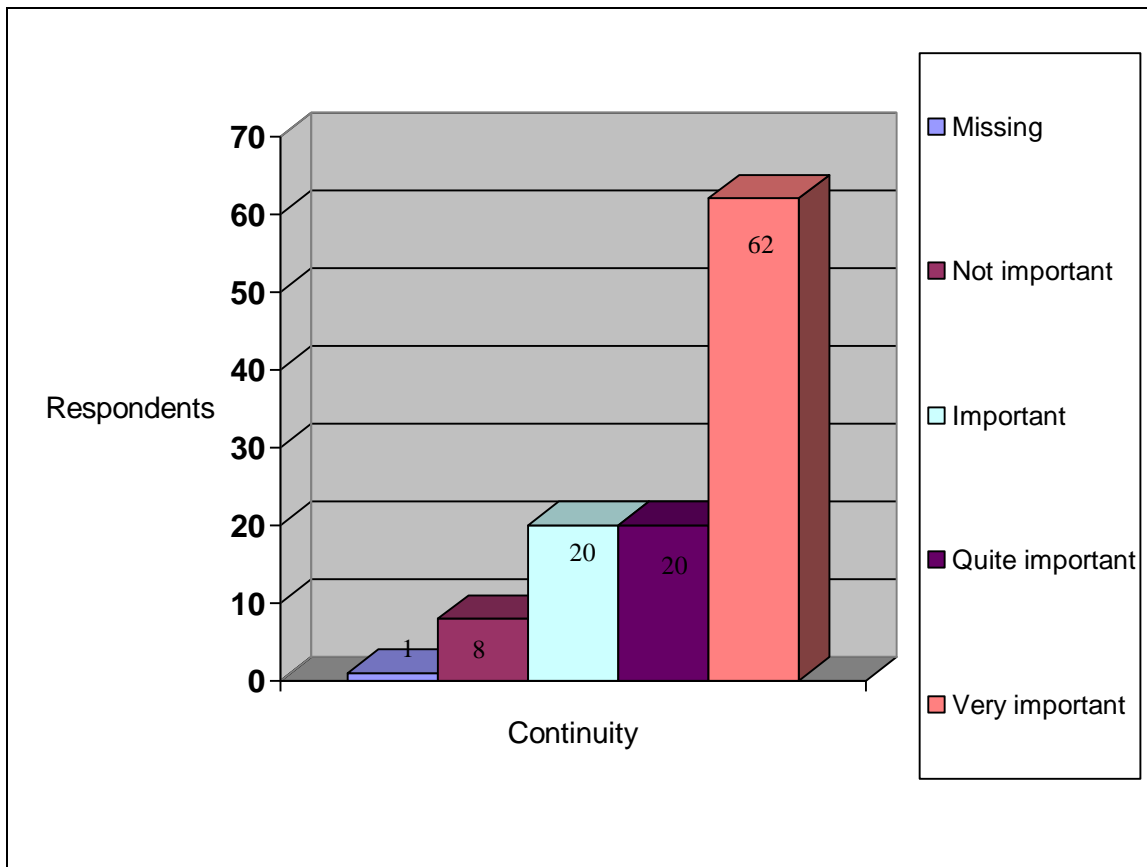
Information about what the patients can do for themselves was scored by 62 (55.9%) of the respondents as being very important. Some work has been carried out regarding exercise and cancer recovery (Mutrie et al. 2007). As new work comes into the public domain, follow-up is the ideal opportunity to impart that information to patients (Figure 10).

**Figure 10 - Benefits for information for self-help**



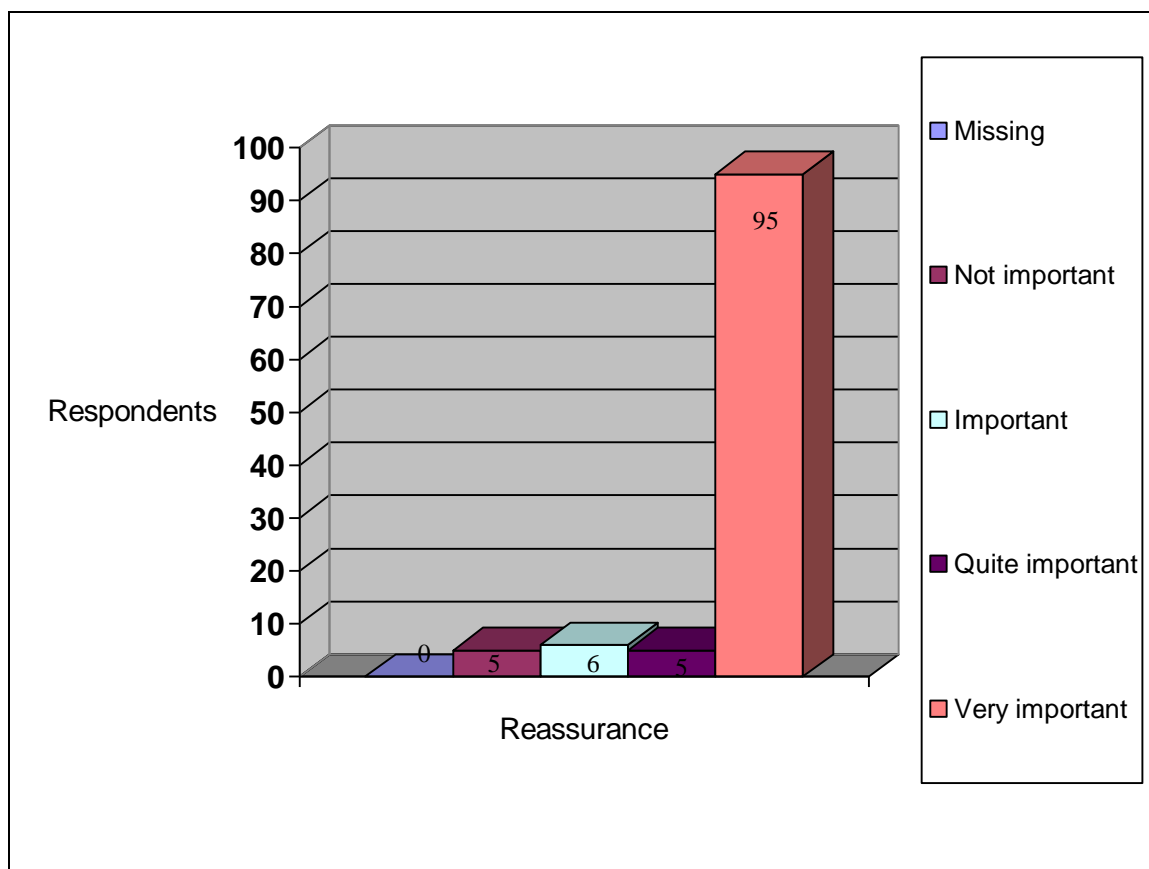
Sixty two (55.9%) of the respondents felt that being sure of seeing the same person as 'very important' (Figure 11). Pennery et al. (2000) suggested that continuity would improve professional relationships and Adewuyi-Dalton et al. (1998) agreed that the building of relationships was important to women who face uncertainty in relation to chronic illness.

**Figure 11 – Benefits of continuity**



Reassurance was scored as 'very important' by 95 (85.6%) of the respondents (Figure 12). The word cancer has the connotation of a deadly disease and of a threat to life. It requires adjustment to life and the ability to cope with the fear that the disease may recur. Women express the need for regular check-ups and the need for reassurance.

**Figure 12 - Benefits for reassurance.**



There is no statistical significant association between demographic variables, disease stage or treatment and the responses relating to patient views of the current service.

## **6.5 THE ACCEPTABILITY OF DIFFERENT TYPES OF BREAST CANCER FOLLOW-UP CLINICS.**

Respondents were asked to score how acceptable it would be to see their GP for cancer follow-up. Fifty two (46.8%) of respondents felt that this was an acceptable mode of follow-up care. However, 57 (51.4%) of them felt that GP follow-up was not at all acceptable.

The respondents were asked how they felt about the breast care nurse attending the surgery to hold breast cancer follow-up clinics. Thirty-five (31.5%) of them scored her attendance as not being acceptable. Seventy five (67.6%) of respondents felt that her attendance was acceptable to them for breast cancer follow-up. Ninety eight (88.3%) of respondents would find it completely acceptable to see the breast care nurse at the hospital for breast cancer follow-up as compared with the option of being able to see a doctor, whereas 101 (91.0%) of the respondents unreservedly accepted this arrangement as a method of follow-up. As to the option of being able to see the breast care nurse, 13 (11.7%) of the respondents felt that this was not acceptable. This is at variance with the unacceptability of the doctor which only 9 (8.1%) of respondents scored as an option (Table 15).

**Table 15 - The acceptability of different modes of follow-up**

Type of breast follow-up	Not acceptable	Acceptable	Missing
GP follow-up at surgery.	57 (51.4%)	52 (46.8%)	2 (1.8%)
BCN follow-up at surgery.	35 (31.5%)	75 (67.6%)	1 (0.9%)
BCN at the hospital.	13 (11.7%)	98 (88.3%)	0
Doctor at the hospital.	9 (8.1%)	101 (91%)	1 (0.9%)

There is no statistical significant association between demographic variables, disease stage or treatment and the responses relating to the acceptability of alternative modes of follow-up.

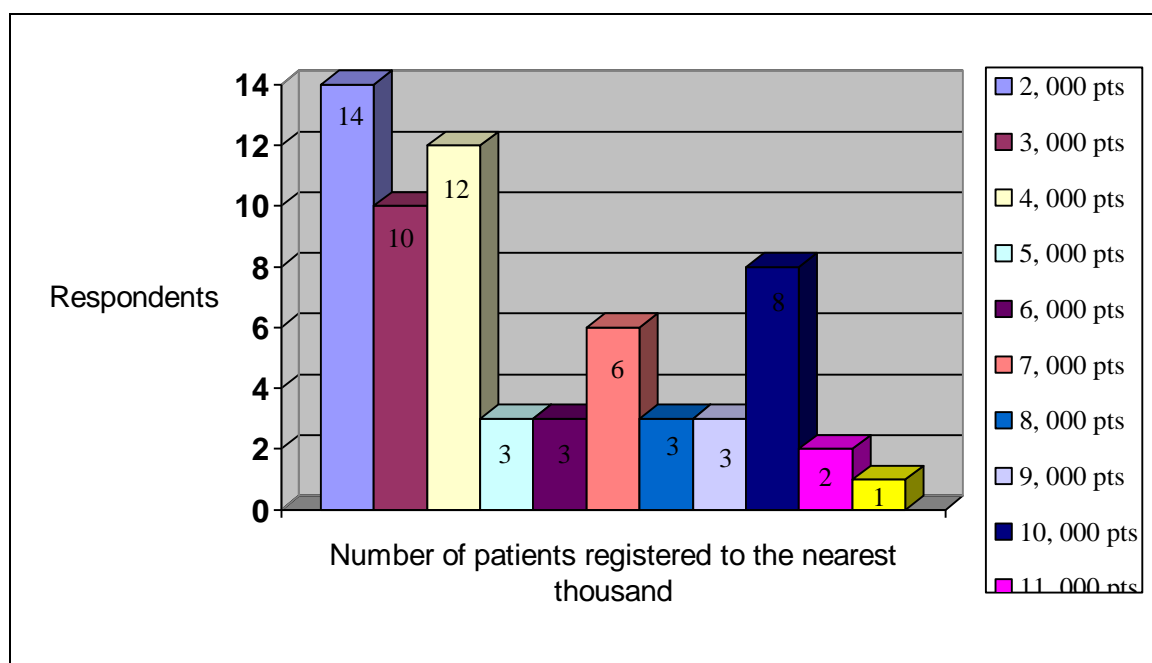
## 6.6 GP SAMPLE DEMOGRAPHICS

From 164 GP practices across a Cancer Network 111 (67.6%) were returned after two mailings. From 111 GPs, who completed the questionnaire, 46 (41.4%) explained they did not use the breast unit mentioned in the accompanying letter. From the sample of 65 (58.5%) GPs, who did use the breast service in the research project, 21 (32.3%), were single-handed GPs and 44 (67.7%) were part of a group practice. Fourteen practices had

2,000 patients; 12 practices had 4,000 patients; and eight practices had 10,000 patients (Figure 12).

Obviously, the response rate from postal questionnaires is critical. A poor response rate can introduce uncertainty and bias (Smeeth and Fletcher 2002). A systematic review of 292 trials by Edwards, Staniszweska and Crichton (2004) shows that offering incentives, such as money, for the return of questionnaires increases response rates. The authors found that simple measures such as sending questionnaires in white rather than brown envelopes also increased the chances of their being returned. Using follow-up phone calls or incentives were more costly ways of influencing the response. In this research project the questionnaire was sent twice in white envelopes which were stamped and addressed. The suggestion of telephoning was considered but concerns as to causing bias were discussed between supervisors and so the researcher decided against pre-questionnaire telephone calls.

**Figure 13 – Number of patients within the G.P. Practice.**



## 6.7 VIEWS OF THE CURRENT BREAST SERVICE.

Fifty six GP respondents (86.2%) felt that attending follow-up gave patients a feeling of confidence in their progress and that this was an important aspect of breast cancer follow-up. Allen (2002) describes an anxiety/relief cycle as an intrinsic part of the follow-up experience which has not been fully understood (Table 16).

**Table 16 - Benefits of attending breast cancer clinics.**

Benefits of attending follow-up.	Not Important	Important	Total	Missing
Access to team	8 (12.3%)	57 (87.7%)	65 (100%)	0
For confidence	8 (12.3%)	56 (86.2%)	64 (98.5%)	1 (1.5%)
Time to discuss	9 (13.8%)	55 (84.6%)	64 (98.5%)	1 (1.5%)
To see the same person	9 (13.8%)	54 (83.1%)	63 (96.9%)	2(3.1%)

Fifty five (84.6%) GPs felt that it was 'important' that patients had time to discuss any concerns which they might have and that this was one of the real benefits to follow-up clinics. Issues of continuity and access to the team were also highlighted as a benefit to follow-up. The GPs were also questioned on their views regarding hospital based follow-up in particular (Table 17).

**Table 17 – GP defined advantages of hospital based follow-up**

Comment	Count
Seeing an expert	37 (56.9%)
Organising tests	22 (33.8%)
Giving reassurance	19 (29.2%)
Seeing the MDT	15 (23.1%)
Being able to sort out problems	14 (21.5%)
Collecting data	2 (3.1%)

In agreement with other work and with previous answers, reassurance remains as being important for 19 (29.2%) respondents. However, 37 (56.9%) of the GPs felt that seeing



the expert was a benefit to hospital based follow-up as was the ability to organise tests, being part of a multidisciplinary team and the availability of resources to sort out problems. Nonetheless, the GPs did highlight disadvantages of hospital based follow-up (Table 18).

**Table 18 – GP defined disadvantages of hospital based follow-up**

<b>Comment</b>	<b>Count</b>
Long waits in clinic	25 (38.5%)
Travel	13 (20.0%)
No continuity	13 (20.0%)
Hospital follow-up is a waste of time	2 (3.1%)
No time for new patients	5 (7.7%)
Very little communication with GPs	2 (3.1%)
Anxiety with hospital follow-up	6 (9.2%)

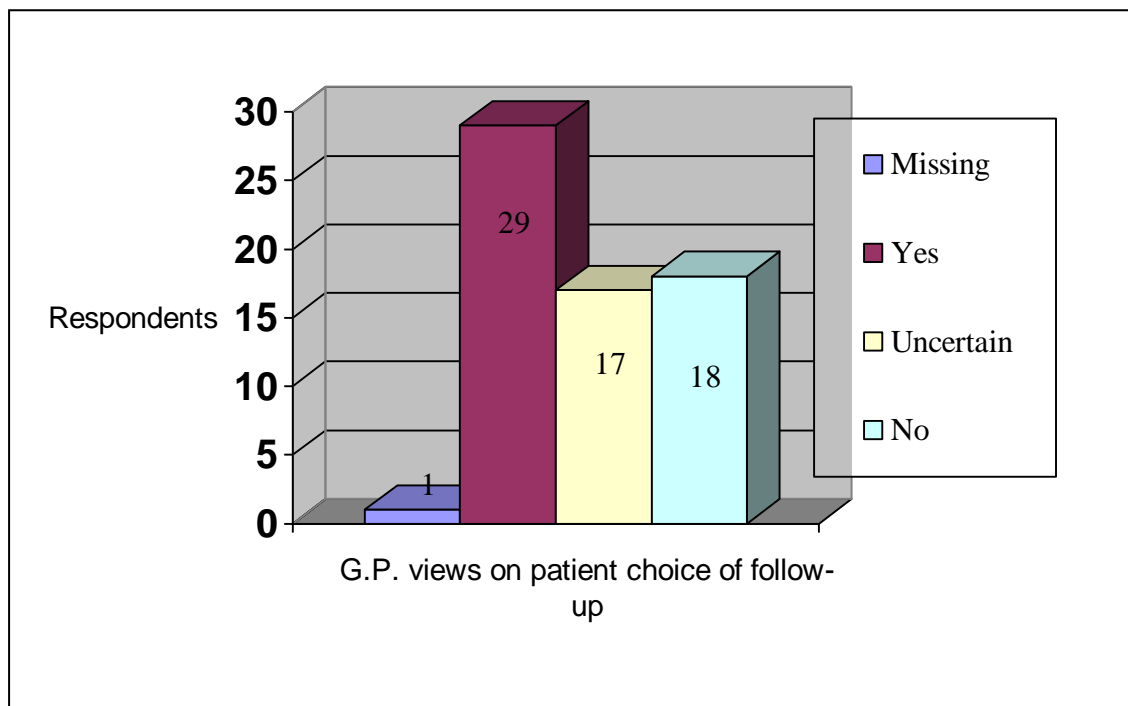
Twenty five (38.5%) GPs felt that long waits in clinic were a disadvantage of hospital based follow-up. One respondent felt that it might not be otherwise if the follow-up was in primary care! Thirteen (20.0%) of GP respondents felt that it might be difficult for patients to travel to the hospital. Some GPs felt that continuity was an important aspect of follow-up but in reality 13 (20%) of them felt that patients might see different junior doctors and that this was a disadvantage to cancer follow-up, based within the hospital setting. Two (3.1%) of the respondents felt that follow-up was a waste of resources and 5 (7.7%) of them felt that, as clinics are organised, there was little time left for new patients. The views on the current breast service did not have any statistical significance in relation to the size of practice.

## **6.8 VIEWS ON ALTERNATIVE MODES OF BREAST CANCER FOLLOW-UP**

GPs were asked for their views on whether patients should have a choice about the mode of their breast cancer follow-up. (Figure 13). There was 29 (44.6% of GPs who felt that

women should be given a choice. Compared to 18 (27.6%) who felt they should not, 17 (26.1%) who were uncertain and one (1.5%) who failed to answer this question.

**Figure 14 – Patient choice on follow-up**



In relation to the acceptability of alternative models of follow-up there was a wide divergence in views especially in relation as to whether GPs should play a greater role in the follow-up of breast cancer patients. Twenty four (36.9%) of them felt that GPs should play a greater role and 37 (56.9%) of them felt that GPs should not be involved in breast cancer follow-up. GPs were also asked whether an option of shared care would be appropriate. 37(56.9%) of them scored 'yes' but 22 (33.8%) of them scored 'no'. (Table 19).

**Table 19 – Modes of follow-up acceptable to GPs**

Mode of follow-up	Not Acceptable	Acceptable	Missing
GP at surgery	28 (43.1%)	25 (38.5%)	12 (18.5%)
BCN at the surgery	25 (38.5%)	30 (46.2%)	10 (15.4%)
BCN in the hospital	16 (24.6%)	41 (63.1%)	8 (12.3%)
Seen by the doctor at hospital	6 (9.2%)	55 (84.6%)	4 (6.2%)

## 6.9 VIEWS ON GP INVOLVEMENT IN BREAST CANCER FOLLOW-UP.

The respondents were directly asked whether they would be willing to be involved in follow-up. Sixteen (24.6%) of them agreed that they would like to be more involved. Twenty five (38.5%) of them were not willing to be involved and 23 (35.4%) of the respondents were uncertain about it. GPs were asked whether they felt equipped to carry out breast cancer follow-up. Nine (13.8%) of them felt that they were equipped to do it but 35 (53.8%) of them felt that they were not equipped to be involved in cancer follow-up. Eighteen (27.7%) of them were uncertain about it. If they were to be involved in follow-up of patients, GPs were asked what they would require. (Table 20)

**Table 20 - GP requirements to practice follow-up**

Requirements	Number	Percentage
Funding	50	76.9%
Staffing	46	70.8%
Training	46	70.8%
Facilities	34	52.3%
Access to hospital	17	26.2%
Protected time	13	20.0%
Access to tests	11	16.9%

Funding appears to be the greatest requirement for practice of follow-up with staffing and training coming next as requirements. Seventeen (26.2%) of the GPs felt that quick access of return to the hospital was important as was the ability to organise investigations (Table 21).

## 6.10 SUMMARY

The age, ethnicity and socioeconomic variables of the respondents completing the questionnaires reflected that of the population of the local area. The 111 respondents were asked about their experience of the current breast cancer follow-up service. In line

with the focus group, the women in the survey attended the clinic for reassurance, to gain information about their progress and any new 'up to date' treatments or investigations. To be seen as person and not just a patient appeared to be an important element to care and links with the importance of continuity of care which scored highly and gives patients confidence in the clinical team and their rehabilitation. As vulnerability was discussed in the focus group the respondents experience in relation to privacy and dignity was asked. In the clinical setting this was also an important element of follow-up care along with the opportunity to be listened to if the patient had concerns or anxieties.

The GP interviews discussed shared models of care; this was further investigated in the patient questionnaires. The respondents wanted to be seen mainly at the hospital by the doctor or the specialist nurse but they were not adverse to primary care follow-up and a possible area to be discussed in a new model of care.

The 65 GP's who returned the completed postal questionnaires agreed that the benefits of breast cancer follow-up clinics were that of reassurance, time to discuss anxieties and concerns and continuity of care. However, they did explain another benefit was access to the clinical team at the hospital an important aspect to follow-up. They did give details of the disadvantages of hospital based follow-up which included long waits in clinic, travel and sometimes the lack of continuity of care. Since the GPs had listed the disadvantages of hospital based follow-up they were asked should patients have a choice in where they attend their appointments as this maybe a possible element to be developed in a new model of breast cancer follow-up.

As the GP interviews discussed shared models of follow-up with systems in place between the hospital and primary care the GPs were asked their comments to a proposed shared model of care. In line with the GP interviews this may be an area of further

development but there were educational and resource issues which would require further development with strict guidelines, policy, financing and systems in place to ensure patient safety. As there was consistency of findings since the GPs and patients were mostly in agreement about the core role of follow-up to provide reassurance and continuity of care to the women, a new model of follow-up could be developed with these core fundamental elements of care.

## **CHAPTER SEVEN**

### **DISCUSSION**

#### **7.0 INTRODUCTION**

In this chapter the findings, discussed in previous chapters, are explored in relation to the initial aim of the research and the objectives of the study. Key findings will be highlighted and considered within the theoretical framework that underpinned this study to yield a new model of breast cancer follow-up care. Uniquely this study has the views of the different disciplines and patients and their views are often consistent with each other as they have an understanding of the complexities of breast cancer management and follow-up. This data will contribute to the full picture of breast cancer care at the follow-up stage, in order to develop a new service incorporating all their views. In this chapter the theoretical framework will be discussed in relation to the key issues in breast cancer follow-up. Incorporating the findings from the study in the theoretical framework will allow a new model of breast cancer follow-up can be developed.

#### **7.1 KEY ISSUES IN BREAST CANCER FOLLOW-UP.**

The findings from this study generated several key themes about the experiences of breast cancer follow-up. The primary issues indicate the importance of assessment when standardising follow-up care. It is important to use a benchmark to aid recovery, refer on when there is a concern and incorporate an audit tool to audit follow-up practice. The themes which have emerged from the participants' experiences will be discussed in turn. They are as follows:

- Reassurance – a key aspect to follow-up.
- Communication – a key aspect to follow-up. .

- The process of follow-up.
- The importance of continuity of care.
- Expert opinions.
- The importance of information and education.
- Alternative models of breast cancer follow-up care.

In this study the research explores the user's experience through both the user (direct) and the professional (indirect). The results from the study showed the fear of recurrence as the main reason why women attended breast cancer follow-up clinics. Others reasons, such as information, continuity of care, privacy and dignity, were important but these aspects to care, when met, enabled the patients to feel empowered and able to cope with this life threatening illness and fear of breast cancer recurrence. From the data it would appear that some women require more support than others, depending on each individual. However, at present all patients are followed up in the same manner regardless of disease or social, cultural and environmental variables.

#### **7.1.1 Reassurance – a key aspect of follow-up.**

The results from the research indicate that women attend clinics to gain reassurance and this is also reflected in the existing literature (Revenson et al. 2005). Clinicians in this study have discussed the changing of follow-up in line with new NICE guidelines (NICE 2002). At no point in the NICE guidelines are the views of the patients explicitly considered nor is the issue of reassurance discussed. From the survey data it has become apparent that most women gained confidence from attending the clinic and found reassurance from this. When asked about the purpose of attending follow-up clinics, 77 (69.3%) of them felt that the whole purpose of the clinics was to give reassurance. The GP interviews concurred with this view and the GPs felt that it gave the women confidence

in their progress. It is recognised by caregivers - but not by the guidelines - that reassurance is of primary importance to patients, GPs and the MDT.

The findings highlighted the safety net that follow-up provided and the comfort that the patients felt when they knew they were going to be seen. The important new data indicated that there was a need for an official face to face check/examination, perhaps, to validate their recovery. This does not concur with current literature – Beaver et al. (2009) compared, in Manchester, hospital and telephone follow-up for 374 women who were low to moderate risk of recurrence and found telephone follow-up well received. The Manchester study does not clarify the definition of low to moderate risk and whether the women had received hospital follow-up first and then randomised to telephone follow-up. From this study the data highlights the examination as an important element to validate recovery and this is consistent with patients, GPs and the MDT. Beaver et al (2009) does not have the views from GPs or the MDT, only the women. In this study patients reported that there were variations in this examination but it was a routine that was expected by them and their families. The issue of the examination is an important point in changing clinical practice. It is a central part of follow-up and variations of practice cause concern. The MDT also commented on the different ways patients were examined. Therefore consistency of examination technique and competency needs to be developed by the staff providing the service. In addition by attending the breast clinic the women in the study received information regarding changes in treatments and investigations, if required, and this gave reassurance as they wanted to know that they were well and disease free. This data is compatible in the existing literature (Allen 2002).

Members of the MDT highlighted how breast cancer follow-up emerged from a surgical premise that historically has now evolved into acceptable practice. They explained how surgeons operate on the women and feel that their role has ended there and that the



patient needs to come to terms with her situation. In comparing breast cancer with other illnesses there were comments made by the MDT regarding reassurance but they pointed out that this reassurance was also required for all life threatening illnesses, and they wished to know what it was that made breast cancer different. An example of a life threatening illness, such as a myocardial infarct, was used to illustrate the lack of support for cardiac patients psychologically and wondered why breast cancer patients should require this support. It could be argued that in clinical practice psychological support is required for all illnesses and this continued drive for the separation of physical and psychological dimensions of illness needs to be addressed in order to provide seamless holistic care for all patients regardless of the their illness. It appeared to some members of the MDT that there was a 'scoring' of illnesses which were competing with each other to gain adequate care.

How women will cope with illness needs to assess throughout the care trajectory from diagnosis to follow-up. This is multifaceted but the situational component to the conceptual framework will identify aspects of everyday living and it influences the way in which people cope and comply with illness and treatments. This includes specific characteristics of breast cancer and its treatments as well as other major and minor life events, such as holidays, weddings and employment, which will affect the timing of treatments and the attendance at follow-up appointments. Many patients find the demands of illness and everyday life difficult to balance, thus causing them to feel a lack of empowerment (Elmberger, Bolund, Magnusson, Lützé, and Anderson 2008).

The interpersonal context of the framework includes both formal and informal support, family and friends and the professional groups. Evidence shows that the influence of family and friends on psychosocial adjustment to illness is positive. With the support of others, patients are able to cope well physically with treatments and hospital routines and

not to feel emotionally isolated. Family and friends validate treatment choices, gather information and help make sense of illness (Revenson et al. 2005). In follow-up the support of others will assist patients in making decisions regarding changing adjuvant treatments and keeping surveillance appointments. Obviously some social support can become very controlling and it is important that health professionals are aware of this as it can lead to distress and resentment on the part of the patient (Lewis and Rook 1999). An example, as used previously, is a delayed breast reconstruction where the patient would like to have this procedure carried out but her partner does not want this to happen. Discussions around reasons for and against breast reconstruction, clear information and an understanding of what the patient really needs to help with rehabilitation are paramount.

Haylock et al. (2007) have developed a 'Prescription for living' in the context of surviving cancer and its treatments. It is a 'work in progress' at present but the template could be adopted for breast cancer follow-up in the UK including themes from the data from this study could be applied locally. It includes medical details of treatment and diagnosis and also contains a guide for planning healthy life styles. It would need to be validated in clinical practice and developed across cancer networks. It should also include a section on education regarding recurrence, breast awareness and assessment on social support and psychological review following diagnosis and treatment. It is important that there are discussions with the patient and her family related to coping strategies after cancer treatments and about what to expect in the follow-up setting. This assessment tool is discussed more fully in the final chapter.

This study indicates that psychological support in practice has not been standardised in the same manner as clinical treatments despite the fact that the study data gives rich testimony to the reassurance gained by these clinical appointments. The absence of

anxiety and depression does not imply the absence of other psychological difficulties. Burgess et al. (2005) describe more subtle concerns regarding the loss of hope and uncertainty about the future. From the findings, it would seem that psychological interventions would help the patient and that there is clearly a need for a comprehensible psychological assessment to ensure that the clinician understands the issues for that patient and her support mechanisms. Involving family and others at diagnosis and initial treatment is commonplace but this needs to be encouraged within the follow-up setting. In line with the implementation of the guidelines for improving supportive and palliative care services for adults with cancer, commissioned by National Institute for Clinical Excellence (N.I.C.E.) psychological interventions need to be taken into account. The broader social context of cancer should be assessed, including interventions to improve social support. Improving social support may also limit chronic depression, anxiety, or both, in those women who lack an intimate confiding relationship. In considering the above the question can be asked as to how real reassurance is and how follow-up is a multidimensional, clinical activity. This clinical activity is key to in providing follow-up care and may not have to be done by the doctor but is the MDT responsibility.

It has been clearly demonstrated by the women, the MDT and the GPS in this research, as well as, existing literature that the need for reassurance, confidence, psychological support and quality of life are important to women who have been diagnosed with breast cancer. Nonetheless the priority in cancer management remains the treatment modalities and the reality is that supportive care remains the 'Cinderella' of care as it now stands (Willard et al.2005).

### **7.1.2 Communication – a key aspect to follow-up.**

The users did not discuss set times for consultations but there appears to have been a self-imposed time restraint in consultations. It appears that the users were experiencing an increased time pressure due to the workload of clinics, which affected the freedom for them to talk about their problems. By taking responsibility for time the patient felt that she was alleviating the burden of work for the doctors and this confirms the findings of Pollock, Grime, and Mechanic (2002). At present patients in the outpatient setting do not know the length of the appointment time slot between one patient and the next. To explain the time for consultation, and the possible flexibility of that time, and to promote a general awareness on the part of the team of patients' anxiety regarding time would facilitate new ways of working. Jones et al. (2006) suggest that the availability of a confidante, who is able to provide support as needed, would meet the patients' needs more adequately than the current outpatient model which Roland (2002) describes as a "pack 'em in 'nd sell 'em cheap" model. The time between outpatient appointments needs to be negotiated to offer patients time to talk if they so wish. Some people, regardless of disease status, require a lot of time to discuss issues and to seek support whereas other people do not. The findings indicate that all people want reassurance but not all in the same way.

Linked with time in the consultation the opportunity to talk appears, in the view of the focus group, to hinge on the relationship with the clinician. It was important that someone was there to talk to and this facility to talk seemed to give confidence and was deemed to be a part of the therapy just like other cancer treatments. In the focus group the opportunity to talk appeared to be an area that was not being addressed in the clinics. The women vividly described how they had been rushed and how this had adversely affected the consultation. The responses to the questionnaires demonstrated a similar pattern. Nearly one in five, 19 (17.1%) women felt that they did not have enough time during the

consultation. More importantly, the findings clearly indicated that 'being listened to' was very important to everyone and required time. From the emotive discussions during the meeting of the focus group the data, expected from the responses to the questionnaires, would have been that more patients were dissatisfied about the lack of opportunity to talk. Granted that, time, is an area of concern for some but not for as many as was expected. The focus groups may have encouraged more discussions, as has been stated previously, than the calculated scoring in the questionnaires. Therefore the methods used to collate the data may influence the outcome. Furthermore, the focus group comprised of women who were treated some time ago and had joined a 'support group'. The sample of women who completed the questionnaires was a convenient sample not purposeful, they were waiting to attend their appointment and were possibly anxious and so they may not have had a clear memory of their last appointment and the time constraint of the consultation may have affected their response. It is recognised that these factors may have influenced the data returned. Some people, a minority, will have negative experiences and a poor consultation in the follow-up setting. This is extremely upsetting for the patient, causing her to doubt the success of treatment coupled with an experienced invasion of her privacy and integrity. Clearly, this is remembered, and probably more vividly so, than a good experience and makes people angry and more likely to complain. All those pleasant experiences and commendations are less likely to retain a high profile in the memory of the patient.

The opportunity to talk and provide support is clearly important to those who have been diagnosed with breast cancer and GPs, and the MDT describe it as important part of follow-up which is new data. Elevating the position of supportive care depends on organizational issues within the Trust. As the medical director stated, practices need to change but this is difficult in an environment inundated with targets and periodic change.

A CNS in the study describes the ability to provide supportive care as the 'stuff of magic'. and points out that providing support is a complex process when clinicians perceive their role to be rooted in treatment and feel that supportive care is 'doing nothing' (Koedoot et al 2004). A new model of care requires evaluation of the rituals in follow-up, re-evaluation of the CNS role and support from organizations to make the change (Brooks and Brown 2002). The 'time to talk' theme may encompass supportive care and maybe should be outside the clinical setting.

Data from both the focus group and survey felt they did not have enough time to discuss all the issues within the consultation. As stated before social networks are important to ensure that patients have adequate support and are not isolated. Sammarco (2001) found that social support had a positive relationship with the quality of life. Therefore, the patient's community and family networks should be assessed and if women who are diagnosed with breast cancer are continually assessed and care is targeted towards the vulnerable, this will have the best clinical outcome. As the pathway for clinical psychological referrals in the cancer networks now stand, there is some inequity between the centre and the unit and although the attached cancer centre in the study does have clear lines of referral it is based in a city and often not close to the patient's home who live near the cancer unit. The cancer unit in the study did not have clear lines of referral for patients with psychological difficulties and thus it necessitated firm protocols to allow for quick and targeted interventions for these patients. This 'hub and spoke' plan of care is replicated throughout cancer networks, especially for specialist oncology and oncoplastic services (DOH 2000 Cancer Plan). Psychological services are also organised in this manner but members of the MDT felt it did not meet the needs of patients, who are finding it difficult to cope with uncertainty and who feel demotivated by the prospect of long journeys.

Often the timing of illness in a person's life has an impact on the patient (temporal). A diagnosis of cancer to a young person is much unexpected. The fear of recurrence is high for the young and often associated with more aggressive disease. If a person has a less aggressive cancer there is more time to come to terms with the different treatments and with a change in life style. However, in the case of a young person and/or in the case of aggressive disease, situations change very quickly and do not allow the person to cope with illness gradually (Revenson et al. 2005). This needs to be considered in follow-up to give people time to come to terms with their changing situations. Regardless of disease stage or age, each individual has different issues which need to be considered. Therefore, a follow-up plan needs to be individualised. A young working woman with aggressive disease will require different follow-up support and management than would be required by an elderly woman. The young woman's fears regarding the rearing of her young children, the follow-up investigations, following surgery, chemotherapy, radiotherapy, Herceptin and hormonal manipulation, will be different from the fears felt by an older woman who has had hormonal treatments only. Temporal issues regarding the timing of appointments and the commitments of a young working mother and issues of transport and commitments of the older woman's family who may be involved in her care, will need discussing. The data from the MDT, GPs and the women did highlight the importance of having time to talk and therefore an important part of follow-up. This would need to be incorporated into a service development taking into account the temporal and individual needs of the patient and family.

### **7.1.3 The process of follow-up.**

There emerged a difference of methods between different staff members in doing the examination has been discussed earlier in this chapter. The examination was an

important part of the consultation and the validation of wellness and therefore reassuring. In association with the breast clinical examination were conversations about privacy and dignity. The focus group described how their integrity had been breached and how frustrated and angry it made them feel. It would appear that the process of getting undressed and dressed in front of someone and talking with the doctor while in a state of undress created a feeling of vulnerability.

It was a disturbing but instructive experience to listen to the focus group when the women explained in detail how their integrity and dignity had been violated. How angry it made them feel to be treated by another human being in such a non-caring, unempathetic way, especially prior to the consultation! The patient was so anxious and perplexed with fear that the cancer may have returned. Despondently, as stated earlier, the specialist nurse felt that “only with the help of magic could the patient expect to receive the care which would meet all her needs”. With the different disciplines she felt powerless to bring about change. This was in stark contrast to the specialist nurse’s holistic role where she meets with the patient to discuss treatment options and assess the patient outside the clinical setting. She gets to know the patients and their loved ones and her professional relationship with the patient develops and remains over a number of years. The MDT did not refer to the difficulties of the outpatient environment or to the rushed consultations which at times invade women’s dignity but the GPs did comment on the time the MDT have with patients during consultation and by changing the format it may allow complex patients more time and meet their needs. This is the benefit of this study that all the views of the stakeholders are valued and will influence service development. The MDT did discuss treatments, outcomes and the reassurance gained from follow-up. The ward nurse similarly did not discuss the clinic experiences because, for an inpatient on a ward the episode of care differs from short timely discussions and examinations in a clinic to a stay in hospital for a set procedure. On the other hand, in the focus group discussions and



in the results of the survey data there were pockets of good practice that signified integrity and compassion and the women appreciated this care and attention. The positive experiences in the clinic referred to the facility of being able to get dressed and to go into another room or area to talk afterwards and also to the ability to measure the examination. The women wanted to see the consultant at every visit but they understood that this would be impossible to achieve in practice. They had a relationship with the consultant who inspired confidence and they referred to other elements of his 'bedside' manner which made them feel confident. The feeling of confidence is a key component to breast cancer follow-up and again linked to reassurance, as discussed earlier.

The clinicians did not mention this aspect of care but the survey data highlighted this objective as being met within the current service, a view which was at variance with the opinions as expressed in the focus group discussions. As stated previously, the timing of the questionnaires prior to the patient's clinic appointment and the possible anxiety preceding the consultation may have influenced the patients' perceptions. The Department of Health set targets in relation to dignity and privacy in its document 'Essence of Care' (DOH 2001). This document has been widely publicised but it is difficult to ascertain whether health professionals had the time or the resources to put the principles into practice. Woogara (2005) describes how the privacy of patients has been played down and how it is the 'little things', for example, as described by the women of the focus group, introducing oneself and respecting the patient's modesty, that have been forgotten.

Mairis (1994) found that 'respect', 'personal' and 'privacy' were the words most frequently used in the context of dignity. Article 8 (1) of the Human Rights Act 1998 states that: 'Everyone has the right to respect for his private life.' (Office of Public Sector Information 1998). The routine examination involves the exposure of the patient's breasts. This is a sexual part of the body and only uncovered with permission. The examination and

diagnosis of breast cancer is a crisis for the patient as is eloquently described by the former editor of the New York Times, the late Anatole Broyard (Broyard 1992). For the MDT this is a routine procedure. The word 'patient' comes from the Latin 'patients', meaning 'enduring', 'bearing', or 'suffering', and refers to an acquired vulnerability and dependence imposed by a changing health status. Relinquishing autonomy is no trivial experience (Murata 2003). The psychological costs vary from accepting clinical appointments or hospital routines to treatment choices that are incompatible with life itself. To feel threatened to the point where we are no longer the person we once were can cause despair and affect mind, body and soul (Chochinov 2007). The need in health care to achieve cancer targets and to ensure that the patients are seen before breaches of Government Guidelines has its echoes in Roland's (2002) description of "pack 'em in 'nd sell 'em cheap" model. This can be achieved in many ways, such as ensuring that patients are covered appropriately during breast examination, that clinic rooms are locked during procedures, that staff explain issues and procedures. Chochinov (2007) points out that there are core values of kindness, respect and dignity. Just as the simple 'A.B.C'. summarises the fundamentals of critical care, an easily remembered mnemonic of dignity-conserving care may remind practitioners about the importance of caring *for* as well as caring *about* their patients (Peabody 1927). While it may prove difficult to define dignity, its absence in care is far easier to identify. In keeping with issues relating to the environment of the clinic setting, the focus group and MDT members mentioned the explicit nature of breast cancer and the sexual aspect of examination, the effect of breast cancer on a woman and the predominance of male clinicians. As confirmed by the study findings, the patients' perception of themselves is a powerful vindicator of their dignity. All patients wanted to be seen as a person more than as a patient. When this basic tenet is incorporated into care, the patient's sense of dignity is more likely to be upheld and this is confirmed in previous research by Chochinov et al. (2002).

#### **7.1.4 The importance of continuity of care.**

It was felt by members of the focus group that follow-up care was fragmented. The women understood how follow-up worked but they needed to see the same person at each consultation. Participants felt that being seen by different people did not enhance the patient–doctor relationship. The women also felt disturbed when doctors had to read copious notes and ask the same questions. This is supported by the document ‘Your Health, Your Care, Your Say’ (DOH 2005a) in which patients described this fragmentation and not only in relation to cancer services but across all specialties. There was also comfort to be gained in the knowledge that the doctor was familiar with the case. They talked about something to build on. They compared their clinic relationship with that of their G.P. - someone who would know them. In the follow-up setting an emphasis on continuity will empower women. Continuity will enable women to gain control by developing confidence in their progress and their team. When patients are diagnosed with breast cancer they are seen by the consultant, which, according to the data, gives the patients encouragement and confidence to cope with this life threatening illness. The same should happen in follow-up for the same reasons.

Most women who completed the questionnaires felt that being seen as a person and not just as a patient was an important need for breast cancer follow-up. However, in this small sample of follow-up patients, almost one in five respondents felt this was a need that was not fully met. Interestingly new data from this study shows fifty four (83.1%) of the GPs commented on its importance and explained that continuity of care instilled confidence in the patient but GPs were aware that it did not always happen in the hospital setting and they remarked that it was essential for good cancer follow-up. The surgical team within the Trust did agree that there was a high turnover of doctors but that, in the oncology team, only the registrar changed. It was suggested by some members of the

MDT and by the GPs that nurse-led follow-up was a way forward. This study shows not only the patients discuss the importance continuity of care but this is supported by the GPs and the MDT. Consequently this element of care needs to be incorporated into the new model of breast cancer follow-up as all stakeholders agree this is an important aspect to care.

When assessing patients at diagnosis and throughout the patient journey the sociocultural aspects of care need to be highlighted in the assessment. The issue of continuity is important because of language difficulties or because an understanding of aspects of care can only be reached through family members, for which permission may have been given in the past, and in this way a professional relationship is developed over time. Obviously this permission needs to be clarified throughout the patient journey but these communications assist with education and awareness and they encourage the reporting of symptoms. It appears that continuity of care is highly rated by participants in this study and, although it is evident in the literature, it is poorly evidenced in practice settings.

In the existing literature continuity of care is described as an element of care that crosses disciplinary and organisational boundaries and is mainly from the patient's perspective. This study indicates that it is important to all the stakeholders. Cancer care in the acute setting is delivered across many sites and therefore care can be fragmented even though cancer policy dictates better continuity for patients (Gannon 2005). In primary care there is a sense of affiliation between patients and their practitioners – 'my doctor' or 'my patient' – which is often expressed in terms of an implicit contract of loyalty by the patient and a clinical responsibility by the provider. In the field of nursing the emphasis is on communication between nurses, the goal being to maintain a consistent approach to care between nurses and to personalise care to the patient's changing needs during an illness (Sparbel and Anderson 2000). From the publication of the Calman–Hine document (DOH

1995) onwards, cancer treatments have been divided into specialties in order to provide care in a logical and timely fashion. The documentation highlights the importance of specialist guidelines and protocols to ensure continuity of care but it does not discuss the processes that are required for their implementation (Haggerty et al. 2003). Patients appear to require a continuity of information in the management of illness and a personal continuity in the work of the team. To promote the empowerment of women in follow-up, information about recurrence, the side effects of treatments and ways of contacting the team need to be consistent. The data clearly highlights the mixed messages that women received regarding breast awareness and the risk of local recurrence. The giving of information also needs to be individualised for each patient. The support mechanisms, the educational background and a set time for delivering information, using an appropriate tool to assess the patient's understanding, should be documented and a clear pathway should be developed and agreed by the patient and the clinician. For patients and their families to experience continuity the important factor is that teams should know what has happened before, that there has been agreement on treatment and that the team, who will care for them in the future, will have this information in full. To allow this to happen the multidisciplinary team need to ensure that they have time, knowledge and information about the patient in order that they may be able to apply competence and ensure the confidence that care will be recognised by other teams involved with their management and synthesis. This arrangement will help teams to understand continuity and to provide a better quality of care (Haggerty et al 2003). The data from the all the service users agree that continuity of care is paramount in developing a new service. It appears the development of a therapeutic relationship with the MDT is important to ensure patients receive information about their illness. The data indicates that to be seen as a person and not just a patient will instil confidence and empower the patient and that nurses maybe in a key position to develop this role.

### **7.1.5. Expert opinion.**

The discussions in the patient focus group and the survey data did not mention the need to see the expert. This is unusual in that all the other service users made comments related to the expert practitioner and recent cancer documentation ('Cancer Plan' DOH 2000), ('Your health, your care, your say' DOH 2005a) highlights the importance of being seen and treated by a specialist who is competent in site specific cancer treatments. Possibly the patients in the study presume clinical expertise and competence and feel that there are systems now in place to ensure that basic standards are established. This implied presumption is echoed by Elwyn, Buetow, Hibbard and Wensing in 2007.

The GPs and MDT members all remarked on the importance of seeking the advice of the expert when being followed up for breast cancer. The GPs did highlight the difficulty of the junior doctors' clinical experience if the system of follow-up changed. However, the clinicians in the MDT did not feel that cancer follow-up clinics were the ideal setting for learning.

Following on from Khatcheressian's et al. (2006) suggestion that follow-up could be carried out in the primary care setting, the MDT in the study felt that this was unacceptable. Rosenzweig (2006) explained that patients have different needs, for example, altered body image, oestrogen deprivation, fear of uncertainty etc., but the MDT felt that this required expert opinion and could not be coordinated by primary care. However, in reality, in clinical practice it could be argued that there is a lack of support to meet this complexity of needs in the cancer units. Nurses in the study pointed out that they do not have clear methods of referral if they require psychological support for breast cancer patients. The Cancer Reform Strategy (DOH 2007) encourages a close cooperation with cancer charities in which services may be able to dove-tail into each other. However, there

appears to be some reluctance on the part of the hospital physicians in the study to share cancer management with primary care physicians as they are not seen as experts. The American Society for Clinical Oncology (Pestalozzi 2007) has produced new guidelines on the management of breast cancer follow-up data and explains how it can be managed within primary care. It does not include new therapies to be used in the treatment of breast cancer. At present the long-term side effects of new therapies are unknown as is the importance of using new imaging modalities. We await the results of new trials in symptomatic management, which have been carried out in The National Breast Screening Programme and in the wider field of oncology. The use of new complicated drug therapies and surgical procedures warrant the knowledge of an expert. For example, there are protocols now in place to switch node positive and oestrogen positive patients to extended adjuvant therapy. The MDT felt that the number of patients with breast cancer in a GP practice would raise concerns regarding competence. However, follow-up by multiple specialists such as surgeons and oncologists after treatment is costly. Grunfeld et al (1996) did indicate that follow-up in primary care was safe but that this was related to GPs who had a keen interest in breast cancer and the MDT in the study felt unsure as to whether that could be applied to the rest of the GP population in the UK. The Cancer Reform Strategy (DOH 2007annex c) visualises breast cancer management in 2012 and it includes long term therapies with the assistance of specialist nurses or routine follow-up in the community by trained practitioners. The reluctance of some MDT members to transfer patients to primary care is new and will need consideration when developing new models of breast cancer follow-up.

#### **7.1.6 The importance of information and education.**

Concise, consistent and clear information is required for all patients to assist with their recovery from breast cancer. Information regarding the signs and symptoms of breast cancer recurrence, the side effects of treatments and what to expect in cancer follow-up

are all important aspects at all stages of the patient journey. In addition to information about key aspects of the clinical management of breast cancer, an educational programme concerning cancer and healthy living will empower patients to take control and make decisions around health. The response to the questionnaires showed information as being 'very important' or 'important' to most women. Not one response deemed information as being 'not important'. This indicates the importance of information in the follow-up setting. Yet just over one in six women felt that their need for information was not fully met. Pennery et al. (2000) found that information was significant in relation to the woman's progress and in relation to new treatments and investigations. In this study it appeared to be difficult for patients to know what they needed to know regarding breast cancer and both hope and fear were evident in their expressed need for information. In the focus group they openly discussed the failure to recognise local recurrence and the failure to practice breast awareness. Much patient information is given at diagnosis. Breast Cancer Care and local information is given by the clinical team and CNS to assist patient choice and informed consent to treatments. In peer review audits ([www.cquins.nhs.uk](http://www.cquins.nhs.uk)) there are no targets regarding follow-up, nationally, when patients should be counselled and prepared as to what to expect within this part of the continuum.

Breast cancer is a complex illness that needs to be viewed laterally and delineated between key aspects of follow-up for each individual and education should be provided around breast cancer, its management and health choices in recovery. Women may not think of the bigger picture and piece the symptoms together. From the MDT interviews the radiographer described a personal experience where a family relation had not connected recent back pain with the original diagnosis of breast cancer. There is a need for education of GPs, patients, carers and residential home staff. One woman in the focus group highlighted a local recurrence, found at a clinic appointment that she had not noticed. The literature highlights the lack of evidence to support this ritual of breast



examination and follow-up (Khatcheressian et al. 2006). If Mary had known what to look for she might have reported the change sooner. The need for clear information is crucial so that patients may be aware of the signs and symptoms of recurrence. In addition, some patients in the study did not associate other symptoms with cancer recurrence and breast awareness was left to the clinical team. Therefore, an education programme would promote a greater awareness. There is a debate regarding the benefit of detecting recurrence towards overall survival. However, there is evidence to endorse the benefit of local control of the disease if local recurrence is detected sooner rather than later (Dixon et al 2008). Obviously in assessing Mary her sociocultural variables such as age, education and socioeconomic status would be taken into consideration before giving information regarding recurrence. Mary's formal and informal networks would also be assessed and included with permission in the information giving.

The comment by the MDT member that follow-up can be managed through support is an interesting concept. As highlighted, the focus group did receive benefit but the groups need to be facilitated to ensure that there is a benefit. Women need to be assessed during the taking of history by the clinician or CNS to involve their other support networks and, as discussed earlier, perhaps short purposeful groups, discussing education or exercise, could be a stepping stone from end of treatment to an individual follow-up programme. The empirical evidence, however, is ambiguous (Goodwin et al. 2001). Support groups expose patients to others who have coped with the condition and can provide feedback on decisions as well as validation of emotional reactions and self worth. However, recent research suggests that support groups with varying levels of social resources may affect participants in different ways and may even be detrimental to some (Helgeson et al. 2000). The experience of Joan, who cried during the group discussions because of her bad experiences, needed to be managed carefully to ensure that it was not detrimental to

others. There is a need to provide avenues for people to come and talk afterwards, if they wish, and this requires a professional to facilitate such a group. As suggested in the literature, there are differences between support groups and self-help groups and the benefit for the participants needs to be paramount (Helgeson et al. 2000). It may be that people have bad experiences and this influences others or they may doubt their own social network and support by comparing their own situation with that of others.

Another aspect of reliance on the clinical team is the power that the team has in having the clinical knowledge to assume control. There is a fear on the part of clinicians that, if patients know about symptoms, they will not be able to distinguish between normal and abnormal and some patients may therefore require more surveillance than others. Cancer is the most feared of diseases and it is therefore difficult to strike a balance between causing anxiety and providing education. The severity of emotional distress is more closely related to a patient's pre-existing vulnerability than to the characteristics of the cancer, and is also more likely to occur at specific points in a patient's experience of cancer (White and Macleod 2002). Once cancer treatments finish and the follow-up stage starts, the patients end the long relationship that they have developed with the cancer service staff during their treatments. This causes a sense of loss and emphasises the need for clear information and guidelines. Others need help to overcome continuing worries, difficulties of coping with intimacy, return to work and fear of recurrence. The fear of cancer returning can lead to a misinterpretation of physiological sensations such as headaches being seen as representing a recurrence of cancer (White et al. 2002).

In order to deliver a new service, these points require consideration and holistic assessment and the taking of 'medical history' which should include a psychological element to ensure that teams provide individualised patient care. All stakeholders agree

that information and education is imperative to care. Again there is consistency between all the stakeholders which is unique to this study. At diagnosis and throughout treatments there are many points that may trigger anxiety; however, in considering follow-up, the end of treatment can be a major cause of apprehension for some patients. Women can experience anxiety, following long periods of hospital visits and support from cancer service staff, and this can cause a sense of loss and a feeling of vulnerability. An 'end of treatment' plan should be developed and an appointment should be made to assist with anxiety and to offer support for those patients, who require it, in a timely and organised manner (White et al. 2002). As stated, some patients find that the diagnosis of cancer enables them to re-prioritise their life, having a greater appreciation of life. However, there are some people who find that, after treatments have ended, they have great difficulty in overcoming continual worries regarding loss and illness and they find it difficult to return to work and to cope with relationships and home management. These patients often misinterpret new symptoms, such as headaches, as representing the development of new cancers. To assist with caring for anxious patients both primary care and specialist units need to have agreed local protocols to refer these patients into appropriate agencies and to have psychological training for all the staff who are caring for these patients. In the physical assessment patients need to be asked about how they are feeling in relation to cancer and its treatments (Table 22 chapter eight, page 242).

Once an assessment is made regarding post-treatment quality of life, information should be given regarding breast awareness and disease recurrence, the side effects of present treatments and dates for investigations. This information should also encompass decisions as to where and when tests will be carried out, how test results will be communicated and when and how medications will be adjusted. The various professionals involved in the patient's care and, most importantly, the patient herself should be equipped

with this information and written information about recurrence and how to communicate with the team are of vital importance.

One member of the MDT felt that the continual follow-up visits were not empowering and that they did not allow people to move on from their original diagnosis. This situation was described as being 'stuck' and was compared to dragging bereaved relatives to a grave against their will. Continual visits to the hospital sustained the 'sick' role and did not have an end to the treatments and did not allow the patient to be discharged back to normal living. It is conceivable that services should be developed for each patient. Perhaps it is possible to negotiate with patients regarding their needs, which may be different according to their previous experiences, their diagnosis and the support mechanisms in each person's life (Frankl and Quill 2005).

There are several concepts that provide a theoretical underpinning for developing and delivering an educational programme for women who have been diagnosed with breast cancer. In this study one respondent did not practice breast awareness and one did not recognise local recurrence. Block and Williams (2002) found in a study of motivating reasoning that people stopped processing new information about preventative health behaviours when such information threatened their existing beliefs. They discuss 'seizing', which happens when people incorporate new information which is in line with their belief structure, but 'freeze' or curtail new information which is threatening. This may account for the behaviour of the respondents in the study. The fear of finding a new lump and the possibility that it may be a new breast cancer or a recurrence is too threatening for some women. The information given to women in this study at diagnosis helps them to take some control and assists them in coping with the diagnosis of cancer and its treatments. However, there is no structured time at the end of treatment to promote independence. At no point in the study were coping mechanisms introduced, changing health behaviours so

as to face the fears of the breast cancer returning. The fear of recurrence represents future threats to well-being, to influencing coping strategies and to clear decision making if new symptoms appear (Vickberg 2003). There is clearly a need for education to counteract the false expectation that follow-up improves survival (de Bock et al 2004a) and to explain the significance of symptomatic change and the importance of reporting change to clinicians. An educational programme would help breast cancer patients and their partners in dealing effectively and efficiently with the side effects of a cancer diagnosis and the treatments of this potentially fatal disease. Education could also increase behavioural control and improve the quality of life, especially in line with the earlier example of the patients in Kimman et al.'s study (2007).

However, an educational programme would need to ensure that the patient's individual informational preferences and coping styles were taken into consideration. Most cancer patients want as much information as possible. Jones et al (2006) refer to two main coping strategies as 'monitoring' and 'blunting' and they state that patients fare better when information is tailored to their own coping styles. In the focus group one respondent could not read or write which meant that information and education would have to be tailored to her needs. The data from all stakeholders indicates that information is important to everyone. It maybe information regarding new treatments or recognising cancer recurrence but it needs to be sensitive and individualised. The entwinement of hope and fear needs to be understood and therefore the importance of the role of the breast care nurse in the study and her availability in the clinic to answer questions if needed maybe a driving force to service delivery. The availability of a confidante and a means by which a patient can engage support is an important part of follow-up care.

## **7.2. ANALYSIS OF MIXED METHODS**

The use of both quantitative and qualitative methods showed some consistency but also contradiction in the data. In this section how triangulation was completed and what the themes indicated will be discussed. In addition reflexivity will be discussed again at the relevant points in line with the results.

### **7.2.1 Triangulation**

The data from the qualitative focus groups, key informant interviews and the quantitative data from the questionnaires strengthened the analyses and assisted unbiased analyses. The interviews were drawn together into one text and coded. The early themes emerging in the process were:

- Dignity.
- Waiting.
- Continuity.
- Health education.
- Reassurance.
- Examination technique.
- Feelings.

Further reading of the data allowed the further sub themes to emerge and with cross checking with the patients, GPs, MDT and supervisors. From that process the key components of the questionnaires developed. The mixed methods allowed for the engineering and exploring of the key issues for the women, MDT and GPs. There was consistency between the two methods used. All the data showed that after a diagnosis of breast cancer reassurance and continuity of care was core to the needs of all the service users and therefore key in service development. Reassurance has a different meaning for each person but there appears from the data that being examined by a doctor or nurse in

the hospital or at the surgery was an extremely important part of breast cancer follow-up. The raw emotion and upset from the focus group highlighted the importance of privacy and dignity and that this was discussed in the group as though it was not met in breast cancer follow-up care as the service is delivered at present. The use of mixed methods by means of the patient questionnaire illustrated that dignity was an important part of care but it was being met as the service was delivered at present. The use of triangulation enhanced credibility and dependability of the data and any potential for bias.

### **7.2.2 Reflexivity.**

Importantly throughout this data collecting and analysis I had to be aware of my identity with subject of breast cancer as a daughter, a nurse, the reading for my first degree and the impact that would have on the research process. I kept notes in a diary form of how I felt before and after data collection, analysing the data, the theory emerging and discussed openly with my academic supervisors. I felt my previous experiences were important in the theory development and also had to be careful not to stifle the important elements developing through the data due to the concern of bias data. I highlighted in note form what were the key issues that influenced my thinking around data collection. For example before the focus group my experiences in clinic where that patients waited over two hours to be seen by the consultant. I thought that would be discussed openly in the focus group but it was not. I had to make a conscious effort not monopolies the discussions as this was not on the patient agenda. Dowling (2006a) describes a similar process as 'bracketing' in an effort to maintain objectivity. Bracketing is described as the suspension of all biases and beliefs about the phenomenon being researched. As I highlighted by beliefs before and after data collection it increased my awareness and changed my behaviour but I felt it impossible to suspend by beliefs and feel that my experiences enriched the data collection as I understood each element or process and was therefore

able to probe very sensitively into the experiences of the women, GPs and MDT in breast cancer follow-up.

### **7.3 ALTERNATIVE MODES OF FOLLOW-UP?**

There are many innovative alternatives to managing follow-up such as nurse-led or GP-led procedures, the use of telephone follow-up or even the discharging of patients. In this section follow-up will be discussed, as it now stands. Uniquely to this study the views not only of the patients are highlighted but the GP and the MDT. In addition the possible changes to the management of breast cancer follow-up.

#### **7.3.1 Nurse led follow-up.**

In breast cancer and other oncology settings, studies have consistently found that nurse-led clinics are safe, effective, acceptable, and cost effective (Corner et al 2002) (James, et al. 1994) (Faithfull 1999) (Faithfull et al. 2001), (Koinberg et al. 2004). Cox et al (2006) suggest that the patient's pre-diagnosis and treatment need medical assessment but that patients in follow-up require psychological support which could be assessed by the CNS.

##### **7.3.1.1 Patients views on nurse led follow-up**

Women were asked in the questionnaires about follow-up by breast care nurses at the hospital and at the GP surgeries. Just less than one in three women did not want follow-up at the GP surgery by the breast care nurse but two in three would be happy with this



arrangement. When viewing the evidence on nurses' involvement in follow-up at the hospital, most women found it acceptable. Therefore there is an importance attached to attending the hospital, but patients have grown historically to expect this service from the hospital. Many cancer documents and the new Cancer Reform Strategy (DOH 2007) suggest the moving of services nearer to the patient's home. This study does concur with this notion but hospital follow-up is preferred as this arrangement is already experienced by patients in the study. One of the benefits, highlighted by a nursing member of the MDT, was that, if follow-up moved from the hospital, it would be less stressful for follow-up patients since new patients are diagnosed at the hospital and are often visibly upset in the clinics.

#### 7.3.1.2 MDT views on nurse led follow-up

In general, the MDT members were happy for specialist nurses to undertake follow-up of breast cancer patients. Patients had a relationship with the breast care nurse and it was felt that continuity was important whether at the hospital or at the GP practice. However, one nurse in the MDT felt that the nurses' involvement in follow-up would be seen as a 'cheap option'. She may have thought this because she could not see past the medical model of care and the huge contribution which nursing has to offer in supporting patients in follow-up. In relation to developing breast cancer follow-up services, there may be a need for a 'mix and match' approach for different patients. Some patients may want to see the doctor but it appears from the results that most patients were happy to see the nurse. Patients want appropriate and timely follow-up and they want to feel that they are being listened to and not abandoned (Cox et al 2006). Keeling and Dennison (1995) and Moore and Estey (1999) make the assertion, that as patients stay a shorter time in hospital, there is a growing need for combined methods of follow-up. Follow-up is seen as an important

aspect of care and help is needed to assist with the transition from active treatments to the period of care which we term 'follow-up'.

#### 7.3.1.3 GP views on Nurse led follow-up

GPs compared the advanced skill of practice nurses to that of specialist nurses who have advanced their cancer skills, which is a natural progression for a specialist nurse. GPs were happy with nurse-led care, 41 out of the 65 sampled (63%) agreed with breast care nurses being involved in follow-up at the hospital. In relation to surgery follow-up by the breast care nurse 30 out of the 65 GPs sampled (46%) were in favour, but a similar proportion of GPs did not agree with nurse-led follow-up at the surgery (38%) because they had reservations regarding the competency of the nurse. Alcolado (2000) highlights the different training of nurse practitioners and compares this with the obligation that the general medical council has, to oversee junior doctor training. There is a need for clarification in relation to the many and varied roles in nursing and particularly in specialist practice. Peck (2000) explains she is a nurse practitioner first; she practices nursing first and incorporates medical interventions secondly. Strict protocols and guidelines, with educational packages, between primary and secondary care to incorporate both physical and psychological care for patients near home, with easy access back to specialist teams, is possibly the future for cancer follow-up.

Psychological concerns after treatment for breast cancer often become more apparent during follow-up (Passik, McDonald, Rosenfeld, Theobald and Edgerton 1998) and there is documentation to the effect that nurses detect more psychological problems than clinicians while doing routine follow-up (Baildam et al. 2004). Nurses focus on wellness, health promotion and supportive care and are therefore in the prime position to develop and coordinate follow-up care. Specialist nurses working in breast cancer care assist with

complex decision making and reporting side effects of treatments. Therefore follow-up should be included in nurse education, which would encourage more nurses to develop these skills and become involved in follow-up support. At present, regardless of where the patient is, it is often the patient or the specialist nurse who reports any side effects of treatments (Haylock et al 2007). Specialist nurses contribute to symptom management, continuity of care which is paramount when cancer treatments range across many centres/units. Access to specialist nurses involved in survivorship and supportive care, as is shown by the data, is clearly important and is central to the philosophy of patient centered care (Willard et al. 2005). However, comments from the study and current literature highlight the struggle faced by clinical nurse specialists to implement supportive care. The Cancer Reform Strategy (DOH 2007) highlights the need for fully funded MDT coordinators who might resolve the dichotomy of current policy targets at the expense of supportive care. This strategy indicates that follow-up should be protocol driven from the community and should be delivered by specially trained GPs or community nurses. The document refers to the availability of 'patient educators' to support patients and to promote community support where necessary. Reference is also made to specialist cancer nurses who will serve local communities on an outreach basis. Much of this document is ambiguous. In this way it is similar to the NICE (2002) document there appears to be no reference to user involvement. One of the key concepts regarding breast cancer follow-up in the data was reassurance and the continuity aspect of care. The importance of this element of care, which is extremely individualised, multifactorial and complicated, has not been discussed in any depth in the Cancer Reform Strategy (DOH 2007). In addition, there is a need for clarity around the role of the community nurse, in breast cancer follow-up, in relation to specialist knowledge, the giving of information and the clinical examination. Moreover, there is need for clarification of the role of the specialist cancer nurse who will serve local communities on an outreach basis. To ensure continuity and to enable hope, nurses can take leadership in defining a new 'normal' for patients after breast

cancer. However, care will be required to ensure clear roles, formal education, protocols and clear links with acute teams if access is required back to the acute trust.

### **7.3.2. Hospital Based follow-up**

It was felt that there were advantages to hospital based breast cancer follow-up as it is known and accepted. More than nine in ten women, responding to the questionnaire, agreed that hospital based follow-up was the most acceptable mode, with almost nine in ten women agreeing that the breast care nurses should be involved in this follow-up. There is something about the hospital that seems to appeal to the patient, possibly knowing the team and feeling a security in the setting of where they were diagnosed and treated. However, these patients had never experienced a service nearer home and so they could not voice an opinion about community follow-up. One might have believed that the age of the patient could have influenced choice but in this study there were no significant differences in the responses across the age groups. As with age in this study, stage of disease did not show any significant difference in the responses. Some disadvantages were pointed out by the users. Long waits were mentioned as were the travel time and the expense that was incurred. Some patients in the study felt that continuity was not always good and that there was a certain amount of anxiety before the appointment. However, Papagrigroriades et al. (2003) were aware of the pre-visit anxiety but they bargained with reassurance for the results. It appears from the research that patients still want to attend the hospital for follow-up. It may be that GPs are not seen to have the expert knowledge in cancer nor the possible critical mass experience in practice to ensure competence (Pascoe, Neal, Allgar, Selby and Wright 2004). However, in primary care GPs deal repeatedly with chronic illness and with the impact of illness on the patient and on loved ones. This appears to be the 'bread and butter' of primary care (Pascoe et al. 2004). One nurse in the study stated that she did not know where to refer

patients to who had psychological difficulties. Research has shown that psychological morbidity among cancer patients in secondary care suggests that only a small number of distressed patients are identified and treated and that there are many unidentified patients requiring support (Wright, Kiely, Lynch, Cull and Selby 2002).

### **7.3.3 GP follow-up**

#### **7.2.3.1 Patient view on GP follow-up**

Patients and MDT members did not find GP follow-up as desirable as other options. However, this research project was completed before the introduction of the Cancer Plan (DOH 2000), including the numerous targets that were set to streamline cancer care. For example the 'two week wait' for urgent referrals allows appointments to be made very quickly. The ability for the patient to see the GP, to be referred to a breast unit and to be seen by a specialist in two weeks will improve the relationship with the GP and promote good working relationships with the acute and community teams. It may therefore encourage patients to have their follow-up with the GP as quick access can be gained back to the hospital if investigations are necessary. However, the data from the study indicated that just under half of the women did want their GP to deliver follow-up care although over half did not.

In this study patients, who were unwell or worried that the cancer had returned, wanted to be seen by a doctor or team member who knew them. Lakhani and Baker (2006) state that the patient values commitment to interpersonal care and continuity, explaining that patients do not like repeating information and that they value attempts to co-ordinate care. This was a theme that emerged from the trajectory of cancer care and was confirmed in this study. In addition, as discussed by Krogstad et al. (2002), the lynchpin of an effective

and efficient NHS will be relationship-based care, with primary care teams responsible for a well defined population. It is thought that by 2012 most health care will be in primary care with referral to specialist services as needed (DOH 2007 annex c). Obviously, clear guidelines and protocols will be in place to ensure that the interface with patients is not disrupted and that care is seamless.

#### 7.2.3.2 MDT view on GP follow-up

The MDT was concerned about issues of competency in clinical practice and the organisation of investigations. For example, women in follow-up have annual mammography and the management of these results caused the MDT members concern. They also felt concern regarding prolonged adjuvant therapies and their side effects and the switching of medications as new modes of treatment modalities arise. At no point did the MDT consider involving the patient or educating and empowering her in order to give her some choice, similar to those of midwifery services. There are guidelines in relation to 'switching' patients from one hormonal manipulation to another and set protocols as to which patient and when. Written information could be given to patients and to those of their GPs who wanted it, confirming these changes and setting out an agreed plan of follow-up care. However, the management of breast cancer does change and, as one member of the MDT mentioned, there may be a need for continual educational support for primary care teams.

#### 7.2.3.3 GP views of GP follow-up

Over four in ten GPs did not think that they should be involved in follow-up while fewer than four in ten of them felt that it could be a valid part of the GP's role. As GPs care for and treat many different illnesses in different national service frameworks, this may be an area to develop. Grunfeld et al. (2006) describes primary care follow-up as safe in the

hands of GPs who have a specialist interest and are providing follow-up care within the community. MDT members are concerned regarding their competency in oncology. There is a need for a rolling educational programme and for clear guidelines. Jones, Latinovic Charlton and Guilliford (2007) discuss the difficulties of diagnosing cancer and using the two week referral when the numbers in general practice are small. Education related to follow-up will assist this knowledge base.

The GP interviews and survey data showed that almost one in four GPs felt that they would like to be involved, although over half of them did not feel equipped. The need for training in breast cancer follow-up was the highest scored 'need' from the GPs. Another facility required would be the staff to provide administration and secretarial support. Fast access back to the MDT was also highly scored, if either the patient or the GP was worried, and the issue of protected time was discussed to allow the GP to provide this extra service.

Breast cancer can recur within 15 years of initial diagnosis and beyond and so follow-up is an ongoing process (Khatcheressian et al. 2006). Government policy hopes to shorten the patient journey and to provide more care near to where the patient lives. The transfer of breast cancer follow-up would strengthen this government aim. In the United States it is thought that patients with early stage breast cancer (< 5cms tumour and < four nodes positive) could be transferred to GP surveillance. In the study site some members of the MDT did not feel that GPs were competent and some GPs felt 'dumped on' and already under considerable pressure without having that pressure increased. The Cancer Reform Strategy (DOH 2007) discusses community follow-up with trained support and investment and with fast track access back to the MDT when necessary.

Nevertheless, there were GPs who would like to become more involved with the follow-up of their patients, as they felt that it might give the clinical team more time not only for new but also for existing patients who have serious complications. However, they talked about 'water tight' protocols to ensure easy access back to the acute setting if the patient so needed. One of the consultants in the MDT felt that, since patients were being treated by specialists, they should therefore have follow-up provided by specialists. Nevertheless Kimman et al (2007) refer to the MaCare trial, which reduces follow-up and provides additional psychosocial support. The outcome of this trial regarding, the reduction in anxiety and in cost, are expected in 2009 but, at present, it is thought that the educational programme can improve the quality of life for patients. Earle and Neville (2004) found that patients receiving both oncological follow-up and primary care were more likely to receive information regarding preventive health strategies than those receiving oncological follow-up alone. Besides, moving care away from the 'fortress' where diagnosis and treatment had happened might improve the quality of life. However, in the study the data differed. Patients wanted to attend the hospital for follow-up care and the MDT members were reluctant to share care this care with the GPs. However, shared care has not been experienced by these service users and it would, therefore, be difficult to comment.

From the data it would seem that some GPs would like to be involved in breast cancer follow-up but there would need to be investment in this to provide education, time and additional facilities. Shared care or outreach clinics by specialist nurses at GP surgeries or community hospitals are all possible options with direct access back, if there was a need for further investigation. Communication with the primary care team should also help to reduce anxiety and improve ongoing care.



## 7.4. SUMMARY

To conclude, there is abundant literature from the patient's perspective about breast cancer and the needs in follow-up. However, this study has the views not only of the patients but themes which concur with the views of GPs and the MDT. Reassurance appears to be the key to the development of breast cancer follow-up and a shared model of care for patients is required which incorporates these key elements of care. GPs who are interested in cancer are to be encouraged by the MDT members. Resourced community based nurses/specialist nurses with the ability to co-ordinate investigations, including mammograms and bone health and a national audit, could provide a means of ensuring the amalgamation of locally agreed protocols. This would be in line with NICE and reduce the cost of hospital visits, provide 'joined-up' cancer care with organised psychological assessment and a greater access to new therapies (Donnelly, et al. 2007).

The study findings concur with the literature related to the reassurance which is gained from attending follow-up clinics and an important element to that reassurance was the physical examination which was agreed by all the stakeholders to validate recovery. However, the focus group findings indicated a variance in examination practice and when it is not preformed well caused anxiety. Therefore the examination is required to be standardised and audited. Policy documents, such as NICE (2002), do not appear to take into account the views of the users and the importance of reassurance as an element of cancer care. It appears that, as follow-up is currently managed, there are elements of dissatisfaction that need to be unpicked and addressed in a different manner. To attempt to develop these elements of care an assessment of social, cultural and psychological support is required. These assessments should be taken on board by all members of the MDT. As at diagnosis, there is a time for decision making and during follow-up there should be set junctures at which to discuss independent living and coping mechanisms to

do so. It may be that during assessment, after treatments have ended, some women will require more follow-up than others - women with no social support, women with other illnesses, women who have not coped well in the past with other life events. Follow-up may have to be individualized, where some patients are discharged but others require more support, thus moving away from the exact same follow-up programme for all, as happens now.

As women with breast cancer are living longer, care needs to focus on survivorship and on issues related to the quality of life so that women may recover from breast cancer, (Revenson et al. 2005). To meet these different aspects of care in follow-up a contextual model of adjustment to cancer is required in clinical practice to standardise care, develop tools to audit effectiveness and provide evidence based follow-up care. The model should encompass patient assessment of formal and informal networks – which is interpersonal - age, gender, social class and educational level – which is Sociocultural - the disease and treatments and other life effects – which is situational - age at diagnosis and life timing of disease – which is temporal. These areas need to be assessed and are interdependent with the patient's family network (Revenson et al. 2005).

The conceptual framework discussed above would assess the patient's roles and relationships as well as other influencing variables. This assessment should be completed at the beginning of her diagnosis and continually updated through treatment and in the follow-up stage. Variables, such as age, gender, socioeconomic status and education, will influence the way in which people understand cancer and cope with the ongoing impact of the disease. These different variables show the person to be an individual and they determine how treatment is given and how life decisions are made and tailored to the illness. Culture determines how illness is defined and expressed and can dictate whether patients follow prescribed treatments, for example, which are paramount

in relation to breast cancer adjuvant therapies. The clarification of medication regimes should be required in follow-up as standard practice for all patients so that difficulties can be discussed and adherence reiterated. The culture of a patient will also influence how that patient will interact with healthcare professionals. In the light of changing population demographics, a cultural assessment will be of great importance to all patients at diagnosis and throughout the patient pathway, especially in the transitional period of follow-up, to assess psychological adjustment and compliance with adjuvant therapies.

From the study evidence there appeared an important element of 'time in the consultation' and this being linked to 'time to talk'. One in five patients did not have time to talk but 'being listened to' was 'very important' to everyone in the survey. Coupled with these elements there does not appear to be clear referral pathways for psychological care treated at the cancer unit. This is inequity of care with the cancer centre. The women wanted to see the consultant at each visit but understood they could not. It was not the consultant but the relationship he had with the patient that was key to the focus group and survey results. It was the relationship that inspired confidence because he knew them and was familiar with the case and this links again back to reassurance. This was also echoed by the 54 of the 65 (83%) GPs that a relationship with patients instils confidence.

Campbell et al. (2002) remind us that the majority of cancer patients starts in primary care with their presenting symptoms and that during treatments patients attend their GPs for advice and support. Pascoe et al. (2004) state that, taking it as given that all cancer patients experience some distress and need psychological care, an integrated care system for the detection and management of cancer is required to meet the needs of all the stakeholders providing reassurance, continuity, information and relevant data. Primary care needs the organisational skills to identify cancer patients as a population, to take advantage of the confidence which existing skills in chronic disease management provide

and to access existing resources (community and acute) to deliver a better service for cancer patients. The data from this study shows a real need for a different model of cancer follow-up and the consistency between all the stakeholders specify the key elements of care to inform a new framework. The strategy for integrating cancer care and ensuring an efficient management of patients will require emphasis on information systems, good communication and appropriate technology.

There was debate with the MDT about primary care follow-up and concern by some GPs regarding the competency of nurse led care. One way forward would be for the MDT to have responsibility for care and the breast specialist nurse provide follow-up near the patient's home. This would meet the needs of continuity, reassurance, clinical examination, provide up to date information and education. She would be able to coordinate adjuvant therapies and collect audit data. Obviously this would have to be funded and made a priority for the Trust service agenda. Some of these themes concur with current literature however there are new data which would be focused on in the new model, not necessarily omitting previous work but focusing on the new to add to the body of knowledge.

## **CHAPTER EIGHT**

### **CONCLUSION.**

#### **8.0 INTRODUCTION**

All areas of research are potentially sensitive but some areas are more likely to be threatening or even damaging to both the researcher and the researched (Gibson 1996). This study investigated women who had been diagnosed with breast cancer and the professionals involved in their health care. It is difficult to define sensitive subject but Cowles (1988) argues that sensitive topics are those that have potential to arouse emotional responses. Some authors are more specific than others in their definitions of sensitive research in that they refer to a particular topic under investigation. These include HIV/AIDS and issues around mental health (Alty and Rodham 1998), cancer (Davies, Hall, Clarke, Bannon and Hopkins 1998; Johnson et al. 1996) terminal illness (Beaver et al. 1999). In this study the process of gathering this information involved direct contact with vulnerable people with whom sensitive and difficult topics were covered, this can be difficult for the participants and for the researcher (Johnson et al. 1996).

A new model of care will be discussed and the importance of standardising practice. Follow-up needs to embed into everyday cancer care using a contextual framework to meet the complex needs of survivorship. Then the local recommendations from this research will be discussed in how they could influence national policy.

## **STRENGTHS AND WEAKNESSES**

### **8.1 DEVELOPING A NEW MODEL OF CARE**

#### **8.1.1. Introduction**

From the degree of consistency of data from the GPs, MDT and the patients there is a real need for a different model of care. The many studies quoted in the thesis regarding cancer and the management of follow-up generates themes from one discipline: mainly from patients. This study has real strength as the data underpinning a new model of care is from all the stakeholders involved in breast cancer follow-up. Each has an understanding of the issues from their perspective and will promote the development of a standardized follow-up cancer service. The advances in diagnosis and treatment of breast cancer mean that people are living longer having had cancer but those who have survived cancer live long enough to develop a sequel (Haylock 2006). Therefore each patient should have a survivorship/follow-up care plan once initial treatment has been completed. In order to develop this model there are three main goals to assist achievement (Haylock 2006).

- Build the capacity to educate nurses, caregivers, patients and the public on survivorship/follow-up issues through professional education both under and post graduate nursing curricula and MDT forums.
- As part of the survival plan develop a MDT approach to survivorship which is measured through internal and external audit and build up evidence based practice for individualised patient care.

- Develop national and international research to develop survivorship/follow-up care and feed into policy development and practice to develop services and inequity between cancer units and cancer networks in the UK.

Follow-up/ survivorship needs to embed into practice as routine cancer care and is the responsibility of all members of the MDT. Evidence should always underpin practice; however, it is not necessary to wait for evidence to meet the needs of cancer patients who have completed treatment. Survivorship care should include information on prevention of recurrent and new cancers, surveillance of cancer spread and recurrence of second cancers. The surveillance should also assess the psychosocial well being of the patient and any late medical effects of treatment. This should entail a 'face to face' appointment with an awareness of privacy and dignity. From this study the data from all the stakeholders agree that an examination/official check is an important aspect to follow-up care. Protocols and systems will need to be developed to ensure the examination is standardised with clinical competencies and referral pathways clearly defined.

Survivorship care may entail a need for interventions for the side effects of cancer treatments and for breast cancer this may include lymphoedema, fatigue, psychological distress and sexual dysfunction and there may also be concerns about employment, benefits and disability. Data from the study felt nurse led care would be acceptable by all the stakeholders. There was some resistance by the MDT to agree to primary care follow-up. This is new and will need to be considered when implementing a new model of care. However, there was consensus that nurse led follow-up in the community was a possibility with the hospital specialist nurse. Therefore care will need to be coordinated between disciplines, hospitals and PCTs. Systems need to be in place locally to ensure easy and quick access back to hospital when worry results are detected and the documentation and communication of non worrying findings. An assessment could be used to offer survivors

a guide for planning care and patient could have copy to aid communication and documentation (Appendix 11). The stakeholders in the study emphasized the importance of education for both the patient and the carer, this assessment tool would standardise information and allow patients to ask about their illness at their pace. The template would need to adapt locally across cancer networks but could be refined to keep accurate documentation, an audit of practice and standardize care. White et al. (2002) assessment could also be used to assess anxiety and depression (Table 21). Empirical research would need to be developed to establish the template's reliability and validity.

Table 21 - Questions for assessing patients' anxiety and depression

Questions for assessing patients' anxiety and depression
How are you feeling in yourself? Have you felt low or worried?
Have you ever been troubled by feeling anxious, nervous, or depressed?
What are your main concerns or worries at the moment?
What have you been doing to cope with these? Has this been helpful?
What effects do you feel cancer and its treatment will have on your life?
Is there anything that would help you to cope with this?
Who do you feel you have helping you at the moment?
Is there anyone else helping outside of the family?
Have you any questions? Is there anything else you would like to know?

White et al. 2002 p. 379.

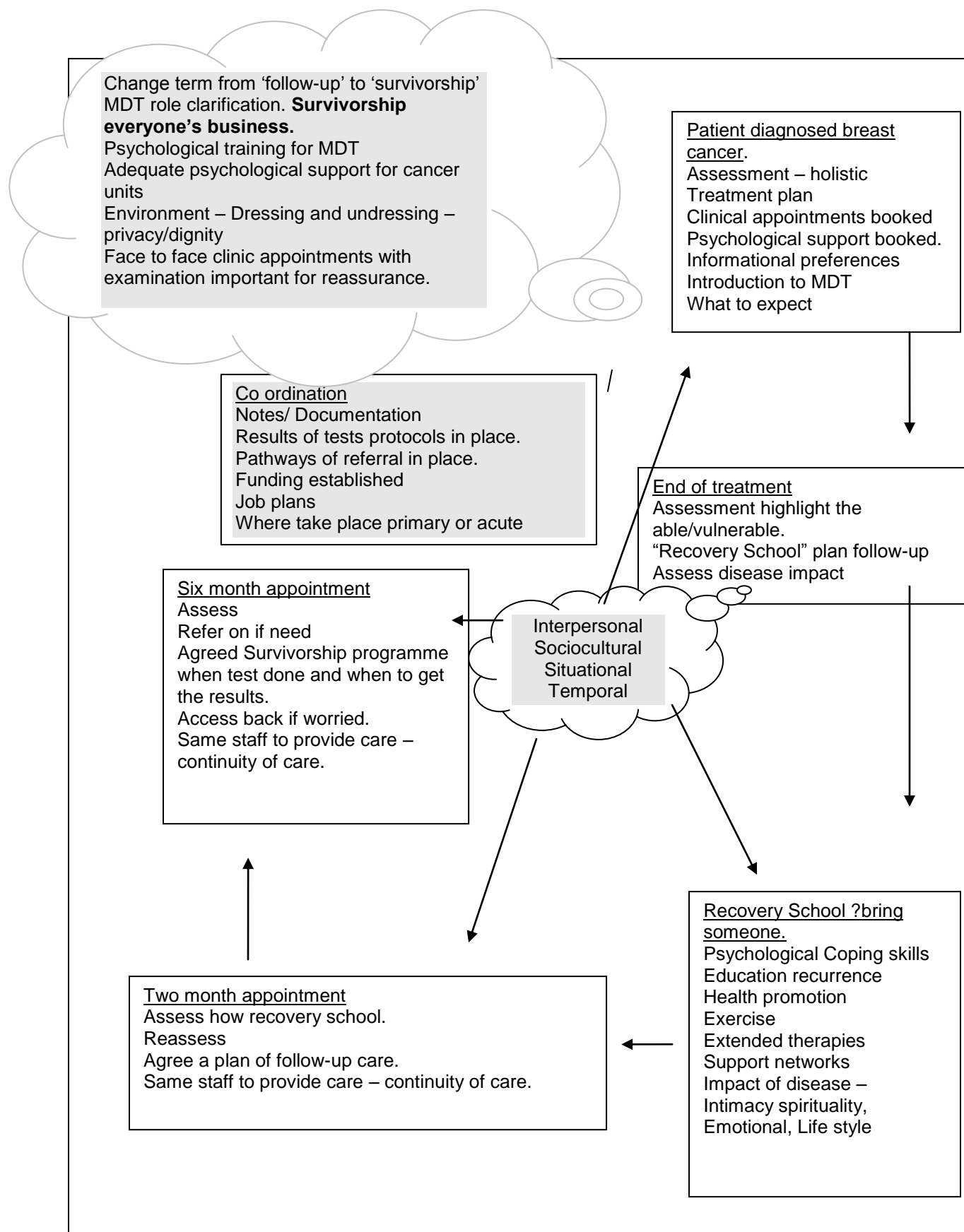
At the end of treatment a formal appointment would be made to discuss what went well during their patient's care and what could we do better? Side effects can be discussed and self care strategies assessed and community based resources. A list of local and national resources and charities that may benefit cancer survivors should be available for survivors. This could include financial assistance, social services, dieticians, exercise groups and local groups that may benefit cancer survivors. Dietary modifications,



acupuncture, massage, relaxation and stress-reduction strategies could also be included with discussion of the consultant oncologist/surgeon to ensure safety.

It will be highlighted that there are difficulties in making change within organizations steeped in roles and rituals and there is, therefore, a need for staff to ensure that there is an infrastructure to support these changes. In line with NHS Trusts, Government is building on the success of the Cancer Plan (2000) and giving clear direction for cancer services over the next five years. There are significant challenges as the incidence of cancer rises and people are surviving cancer for a longer time and the issues in follow-up are therefore important to coordinate. The Cancer Reform Strategy (DOH 2007 annex c) discusses 'cancer visions' which do not represent Government policy at present but give an insight into how cancer services might develop by 2012. The document states that by 2012 a national strategy on cancer survivorship should be developed, stressing the importance of the breast care nurses' role in cancer management and in the coordination of follow-up. Therefore changes in cancer care are led by Government policy and by local initiatives which will assist with the development of new services. Figure 15 shows a conceptual framework of breast cancer follow-up which would meet the varying needs of breast cancer patients in the primary or acute setting.

**Figure 15 Theoretical Framework and the new model of breast cancer follow-up.**



## **8.2 RECOMMENDATIONS FOR POLICY**

### **8.2.1 Making a change to breast cancer follow-up**

To change breast cancer follow-up, organisational change will be needed to eliminate old ritualistic practices. The NHS Plan (DOH 2000a) stresses the importance of working in partnership and divides the territorial boundaries of the professions. The stakeholders in the study agreed a change in follow-up is needed but there was resistance to primary care follow-up by GPs from the MDT which will need to be managed sensitively. From the data the practices in cancer follow-up are deemed useful by all the service users but the national guidelines for follow-up are not clear (Dixon et al. 2008). There is a need to preserve what exists and to promote a new model of care which is evidence based, flexible and tailored to each person's needs (Dixon et al. 2008).

In breast cancer follow-up the different disciplines have diverse roles and therefore different identities. Teams have often worked together for many years preparing for peer review and caring for patients. This means they have shared objectives, which have developed over time, and the team members have a common way of thinking (Brooks and Bate 1994). The culture of the team comprises of collective knowledge, which is maintained through everyday interactions (Brooks et al. 2002). However, the emotional impact of caring for cancer patients, the powerful professional groups who have supreme authority, the habitual behaviour in a large complex health service trust and the repetitive everyday interaction partition professional roles and do not serve to develop innovative practice (Brooks et al. 2002). Therefore staff retention is good but no new ideas are being generated and so practices are fixed and repetitive. To promote change there is a need for facilitation in a way that does not undermine the professional integrity of the MDT. It

could be suggested to move towards shared values and avoid a situation where professionals feel threatened. For example, many patients and GPs in the study mentioned the long waits in breast clinics for all patients. To change the appointment time slots in the PAS system would help with this difficulty. The ritual of ten-minute time slots is out of keeping with patient centred care, it is not evidenced -based and does not take cognizance of The Cancer Plan (DOH 2000) or the Cancer Reform Strategy (DOH 2007). There is a need to discuss operational methods by which the negative aspects of care can be reduced by careful, open and sensitive communication and by managerial support and facilitation. The removal of dysfunctional routines, such as too many oncology/surgical appointments, and a more psychosocial approach to follow-up will serve to unlock the positions of power and culture to relax the systems of control and thus improve the quality of care (Brooks et al. 2002).

### **8.3 AN AGENDA FOR SURVIVORSHIP**

From the study there was agreement of key elements of follow-up from not only the patients but the MDT and the GPs. The need for reassurance was paramount from all stakeholders. To assist with reassurance the data drew attention to the importance of a clinical examination to validate wellness, the importance of continuity of care and education for the patients and carers. These elements of care will be fundamental to the new model of follow-up. The Cancer Reform Strategy (DOH 2007) supports standardising follow-up and has included it as part of its vision. It documents a cancer survivorship strategy but at present does not give clear guidelines on how this may develop and to date has not involved users. The American Society of Clinical Oncology (ASCO) established a survivorship Advisory Group that works to ensure that all ASCO programmes consider issues of survivorship (Haylock et al. 2007). ASCO have also developed fertility guidelines (Lee et al. 2006), as well as guidelines on cardiac and pulmonary late effects but hormone

deficiency and sexual dysfunction are still pending. The Journal of Clinical Oncology devoted its entire November 10, (2006) issue to cancer survivorship and the Institute of Medicine (IOM) in the United States have published a report '*From Cancer Patient to Cancer survivor: Lost in transition*' (Hewitt Greenfield and Stovall 2006). It makes ten recommendations towards raising awareness of the follow-up of cancer after the completion of initial treatment. It defines high quality care for cancer survivors and it suggests ways to achieve it and to improve the quality of the cancer survivor's life. From the study data the recommendations would also include specifics such as the importance of continuity of care, the time to talk and the importance of a clinical examination.

### **8.3.1 Educational Programme**

It is apparent from the data from this study which includes GPs, MDT, patients and the literature, which only focuses mainly on patients, that the fear of the unknown and of possible recurrence is one of the main worries for women who have been diagnosed with breast cancer (Browall, Gaston-Johansson and Danielson 2006). This fear is often difficult for the family to cope with and women tend to hold back their fear so they do not burden their relatives. The support from healthcare professionals with information and education is of significant importance. There are some patients who find the information stressful (Thewes, Butow and Pendlebury 2004) and, therefore, it is important to provide individualised information and to be aware that different age groups have different needs and that involving the patient's family may play a significant part in improving the quality of life and promoting an understanding of treatments and follow-up.

The emergence of new information and the advances in research regarding breast cancer and its treatments will be important for MDT and the GPs in clinical practice. Pierce et al. (2007) describes the importance of physical exercise and how high fruit vegetable intake

may be important after treatments. In addition Mutrie et al. (2007) has published work related to exercise and breast cancer and its impact on the quality of life.

An educational programme should include

- Empowerment/ Psychological issues/ Coping Strategies.
- Signs and symptoms of recurrence
- Diet/Exercise/Fertility/The Menopause
- Health, employment and Insurance

### **8.3.2 Developing a plan for breast cancer follow-up.**

The data emphasizes that follow-up could be managed in the community but the MDT were resistant to GP led follow-up. The data favoured nurse led follow-up in the community by the specialist nurse which would assist with continuity of care. Therefore the roles of providers of primary care and secondary care need to be clear and training in post-treatment of cancer is essential. Specialist practice has led to the fragmentation of the patient pathway. When patients are followed up at different hospitals, a smooth transition depends on the transfer of information from specialists to GPs. The absence of evidence based guidelines on disease survival, health maintenance, and preventative care further complicates the planning of follow-up breast cancer care.

## **8.4. NEW MODEL OF BREAST CANCER FOLLOW-UP**

There are key elements which are important in breast cancer follow-up these have been discussed in the study by patients, GPs and the MDT and strengthened by the breadth of the current literature.

#### **8.4.1 The key elements of breast cancer follow - up**

From the data it was clear that all users felt that reassurance was an important part of breast cancer follow-up. Reassurance appears multi-dimensional and requires systems to be put in place to meet all the users' needs with 'face to face' consultations ensuring privacy and dignity and the ability to refer on if needed. Haylock et al (2007) have developed a 'Prescription for living' in the context of surviving cancer and its treatments. From the study data 'time to talk' is an important part of care and as outpatients in the, hospital setting, are organised, at present, patients are self limiting their time in clinic. This does not give them time to talk. Moreover, the women wanted to 'be seen as a person' not just a patient. To ensure the person she saw for her follow-up appointment knew her and was familiar with her history. This inspired confidence and all links back to reassurance.

#### **8.4.2 The organisation of breast cancer follow-up.**

Once treatment has ended, an appointment should be scheduled for the end of treatment to discuss a plan for follow-up similar to treatment plans at diagnosis. A rolling educational programme for women, covering general breast cancer topics and specific individual appointments for patients, should be agreed for specific investigations. If nurses extend their role to follow-up, then support services will be required to allow them to develop their roles and other non-nursing roles should be removed. These individualised follow-up treatment plans can be agreed by the clinician, GP and the patient and they should be held by the patient and breast unit. The template could be used at the CNS interactions during diagnosis. As the nurse discusses treatment and coping skills, the referral to other agencies can be considered. Discussions should deal with lifestyle factors, such as diet, exercise, alcohol and tobacco use, and referrals should be made for assistance from other agencies as required. Information on complimentary modalities, such as acupuncture,

specific exercise, relaxation and stress reduction are important for patients in follow-up. Dixon et al. (2008) suggest self-complete questionnaires for some patients on the quality of life and continued clinical appointments for people with signs and symptoms of recurrence as well as revisional surgery and or breast reconstruction. Facilities should be put in place for those patients who are suitable for switching to aromatase inhibitors after two years or five years of Tamoxifen. Other issues of bone health, where medication is used, would also need clinical follow-up. Completion of questionnaires or a telephone approach to follow-up causes concern as it may not be an adequate strategy to engage depressed oncology patients, the difficulties of tracking patients who do not reply and does not meet the key elements of follow-up which evolved from the data in the study from GPs, patients and the MDT. There is a need to develop an individual approach to follow-up care, as has been adopted within the diagnostic and treatment stages of the pathway. Time slots need to be expanded for some patients and some women could have open appointments depending on assessment need and changes in circumstances. Flexible follow-up could involve the specialist nurse in providing supportive sessions and onward referral for patients who require further clinical expertise in a new model of care.

The comment by the MDT member that follow-up can be managed through support is an interesting concept. As highlighted, the focus group did receive benefit but the groups need to be facilitated to ensure that there is a benefit. Women need to be assessed during the taking of history by the clinician or CNS to involve their other support networks and, as discussed earlier, perhaps short purposeful groups, discussing education or exercise, could be a stepping stone from end of treatment to an individual follow-up programme. The empirical evidence, however, is ambiguous (Goodwin et al. 2001). Support groups expose patients to others who have coped with the condition and can provide feedback on decisions as well as validation of emotional reactions and self worth. However, recent



research suggests that support groups with varying levels of social resources may affect participants in different ways and may even be detrimental to some (Helgeson, et al. 2000). The experience of Joan, who cried during the group discussions because of her bad experiences, needed to be managed carefully to ensure that it was not detrimental to others. There is a need to provide avenues for people to come and talk afterwards, if they wish, and this requires a professional to facilitate such a group. As stated in the literature review, there are differences between support groups and self-help groups and the benefit for the participants needs to be paramount (Helgeson et al. 2000). It may be that people have bad experiences and this influences others or they may doubt their own social network and support by comparing their own situation with that of others. The opportunity to talk and provide support is clearly important to those who have been diagnosed with breast cancer. Elevating the position of supportive care depends on organizational issues within the Trust. As the medical director stated, practices need to change but this is difficult in an environment inundated with targets and periodic change. A CNS in the study describes the ability to provide supportive care as the 'stuff of magic' and points out that providing support is a complex process when clinicians perceive their role to be rooted in treatment and feel that supportive care is 'doing nothing' (Koedoot et al 2004). A new model of care requires evaluation of the rituals in follow-up, re-evaluation of the CNS role and support from organizations to make the change (Brooks et al. 2002).

#### **8.4.3. The team involved in breast cancer follow-up.**

The data from the study accentuated that nurses were in the ideal position to provide support. This was an acceptable mode of follow-up by GPs, MDT and the women. Psychological concerns after treatment for breast cancer often become more apparent during follow-up (Passik et al 1998) and there is documentation to the effect that nurses detect more psychological problems than clinicians while doing routine follow-up (Baildam

et al. 2004). Nurses focus on wellness, health promotion and supportive care and are therefore in the prime position to develop and coordinate follow-up care. Specialist nurses working in breast cancer assist with complex decision making and reporting side effects of treatments. Therefore follow-up should be included in nurse education, which would encourage more nurses to develop these skills and become involved in follow-up support. At present, regardless of where the patient is, it is often the patient or the specialist nurse who reports any side effects of treatments (Haylock et al. 2007). Specialist nurses contribute to symptom management, continuity of care which is paramount when cancer treatments range across many centres/units and was highlighted in the data by all the stakeholders. Access to specialist nurses involved in survivorship and supportive care, as is shown by the data, is clearly important and is central to the philosophy of patient centred care (Willard et al. 2005). However, comments from the study and current literature highlight the struggle faced by clinical nurse specialists to implement supportive care. The Cancer Reform Strategy (DOH 2007) highlights the need for fully funded MDT coordinators who might resolve the dichotomy of current policy targets at the expense of supportive care.

From the data it would seem that some GPs would like to be involved in breast cancer follow-up but there would need to be investment in this to provide education, time and additional facilities. Shared care or outreach clinics by specialist nurses at GP surgeries or community hospitals are all possible options with direct access back, if there was a need for further investigation. Communication with the primary care team should also help to reduce anxiety and improve ongoing care.

#### **8.4.4 Hospital, Community or shared mode of follow-up**

The Cancer Reform Strategy (DOH2007) indicates that follow-up should be protocol driven from the community and should be delivered by specially trained GPs or community

nurses. The document refers to the availability of 'patient educators' to support patients and to promote community support where necessary. Reference is also made to specialist cancer nurses who will serve local communities on an outreach basis. Much of this document is ambiguous. In this way it is similar to the NICE (2002) document there appears to be no reference to the views of the patients or MDTs who work in breast cancer teams. One of the key concepts regarding breast cancer follow-up in this study was reassurance and the continuity aspect of care. The importance of this element of care, which is extremely individualised, multifactorial and complicated, has not been discussed in any depth in the Cancer Reform Strategy Cancer Vision for care in 2012 (DOH 2007). In the data of this research these aspects of care are paramount. In addition, there is a need for clarity around the role of the community nurse, in breast cancer follow-up, in relation to specialist knowledge, the giving of information and the clinical examination. Moreover, there is need for clarification of the role of the specialist cancer nurse who will serve local communities on an outreach basis. To ensure continuity and to enable hope, nurses can take leadership in defining a new 'normal' for patients after breast cancer. However, carefulness will be required to ensure clear roles, formal education, protocols, clinical competency and clear links with acute teams if access is required back to the acute trust.

## **8.5 SUMMARY**

This study has strength as the views of the women are paramount but uniquely the views of GPs and the MDT are also recorded. There is consistency across all the data in the study which concurs with other literature, which is mainly from patients, but also adds to the body of knowledge new data which are elements of breast cancer follow-up. Cancer is a frightening and life threatening illness. Dixon et al. (2008) are of the opinion that the 20 year survival for breast cancer will be greater than the five year survival rate 30 years ago. Breast cancer is a chronic illness which can recur even after 20-30 years (Dixon et al.

2008). NICE (2002) guidelines for England and Wales recommends two to three years of follow-up and conclude that long term follow-up is unwarranted as no improvement in outcome has been reached from randomized studies. The aim of follow-up, as NICE dictates, is to detect and treat local recurrence, to deal with side effects of treatment and to provide psychological support. Unfortunately the guidelines do not specifically suggest timings of mammogram, as it is felt that they are not sensitive enough to detect abnormalities. The incidence of metastatic disease peaks at two to three years after diagnosis. However, Dixon et al. (2008) indicate that the pattern is different for treatable loco-regional recurrence and contralateral breast cancer. They explain that, even though local recurrence falls with time, the development of new breast cancers in the originally treated breast rises. Therefore follow-up for three years will not meet the NICE guidance.

The women, GPs and MDT in the study commented on the different examination techniques used in follow-up and recent literature comments on the reliability of examination. In a recent Edinburgh audit, only fifteen out of one hundred and ten local recurrences were detected by examination. However, fifty-six were detected with mammography and thirty seven were detected by the patient herself (Montgomery, et al. 2007b). The patients who were diagnosed with recurrence through mammography had a better survival benefit than those who were diagnosed clinically. This is incongruent with NICE guidance which suggests that mammography is not effective in detecting recurrence. Therefore, systems and guidelines, related to timings and funding of mammograms, are essential in the management of breast cancer follow-up. From the findings of the study there is a need for a 'face to face' consultation with systems of documenting and giving results to patients in a timely and sensitive manner will also require investment.

From the data it appeared that some patients felt unsure of what to expect in follow-up and the different routines in surgery and oncology caused confusion. Therefore, there is a

need for information with clear guidelines for clinical teams both in primary and secondary care to ensure standardized practice regarding investigations, life style, side effects and symptoms of recurrence. In making changes to follow-up there needs to be preservation of what is useful but there is also a need to develop a clear model which is evidenced based, flexible and individualized (Dixon et al. 2008). An agenda for survivorship needs to be developed in line with the ASCO advisory group (Haylock, et al. 2007). The ASCO group have developed clear guidelines on the physical impact of treatments and Hewitt et al. (2006) published 'From cancer patient to cancer survivor: Lost in transition' where recommendations are made to raise the awareness of follow-up and ways are suggested of improving the quality of the cancer survivor's life.

The symptomatic burden is significant with long-term treatment and therefore a new model of follow-up care should include medical details of treatment and diagnosis and a guide for planning healthy life styles. This template would need to be validated in clinical practice and it should include sections on education, social support and psychological reviews following diagnosis and treatment. The idea of follow-up in support groups may expose patients to others who have coped but also may be detrimental to others who may have found coping difficult and, therefore, without professional facilitation, not appropriate.

Nurses are in prime position to assist in follow-up and this should be included in nurse education. Nurses contribute to symptom management but from the study and current literature there seems to be an overemphasis of current policy on targets at the expense of supportive care and this tension would need to be resolved before nursing can develop its role in follow-up. GPs are also able to provide follow-up but the data from the study indicates that investment in education, time and additional facilities would be required. There is also the option of shared care under protocol with quick access and good communication with all the relevant teams to improve ongoing care.

The new model of care should assess the patient's ability to cope and it should enhance hope and aid rehabilitation from cancer. A framework, incorporating factors such as personality and disease, is important. An awareness of age, gender educational status and the impact of disease will influence how people cope with the uncertainty of cancer. Important situational events may affect compliance with treatments and appointments and the support of family and friends will help or hinder rehabilitation.

After a diagnosis of cancer, different people have different needs and individualised care, incorporating a multifaceted approach including psychological and social aspects of care, is a way forward. Discharging patients from breast units to the national breast screening programme after two years will not meet all patients' needs in light of the incidence of metastatic disease peaking at two or three years. In addition, the rate of local recurrence does drop but the incidence of new cancers in the treated breast will increase with time (Dixon et al. 2008). Different localities will need to organise care to meet population needs. However, funded and timely investigations are required with systems in place which will communicate results and have the ability to report any concerns with quick access back to the MDT. Patients' needs are varied and therefore follow-up needs to be individualised and flexible.

## REFERENCES

- 'Action for London: A nursing vision for cancer care in the capital 2007-2012'. NHS London.
- Adewuyi-Dalton, R. Ziebland, & S. Grunfeld, E. Hall, A. (1998). 'Patients' views' of routine hospital follow-up : a qualitative study of women with breast cancer remission', Psycho-Oncology. 7, (5), p. 436-439.
- Alcolado, J. (2000) 'Personal views of nurse practitioner and the future of general practice'. B.M.J.. 320, (7241), p.1084.
- Allen, A. (2002) 'The meaning of the breast cancer follow-up experience for the women who attend.' European Journal of Oncology Nursing. 6, (3), p.155-161.
- Amir, M. & Ramati, A. (2002)' Post-traumatic symptoms, emotional distress and quality of life in long-term survivors of breast cancer: a preliminary research'. Journal of Anxiety disorder. 16, (2), p.195-206.
- Alty, A. & Rodham, K. (1998)'The ouch! factor: problems in conducting sensitive research'. Qualitative Health Research. p.275-282.
- Andrews, J. Manthorpe, & J. Watson, R. (2004) 'Involving older people in intermediate care' Journal of Advanced Nursing. 46, (3), p303-310.
- Antman, K. & Gale, P. (1988) 'Advanced breast cancer: high-dose chemotherapy and bone marrow autotransplants'. Annals of International Medicine. 108, p. 570-574.

Aranda, S. (2001) 'Silent voices, hidden practices: exploring undiscovered aspects of cancer nursing'. International Journal of Palliative Care. 7, (4), p.178-185.

Arman, M. (2002) 'Living with breast cancer – a challenge to expansive and creative forces.' European Journal of Cancer Care. 11, (4), p.290-296.

Arnstein, S.R. (1969) 'A ladder of citizen participation' The American Journal of Planning. p.216-224.

Audit Commission (2004) 'Information and data quality in the NHS.' London

Audit Commission (2008) 'The right result? Payment by Results 2003-2007.' London.

Avis, M. Bond, M. & Arthur, A. (1997). 'Questioning patient satisfaction: An empirical investigation in two outpatient clinics', Social Science Medicine, 44, (1), p.85 - 92.

Baildam, A. Keeling, F. Noblet, M. Thompson, L. Bundred, N. & Hopwood, P. (2004) 'Nurse led follow-up for women treated for breast cancer: a randomised controlled trial'. European Journal of Surgical Oncology. 27, (8), p.792.

B.A.S.O. British Surgeons Group of the British Association of surgical Oncology (1995). 'Guidelines for surgeons in the management of symptomatic breast disease in the United Kingdom'. European Journal of Surgical Oncology. 21, (a), p.1–13.

Bass, M. Worster, A. & Wood, M.L. (1996) 'Willingness to follow-up breast-cancer' Canadian Family Physician. 42, p.263-306.



Bassnett, I. Gillis, M. & Tobias, J.S. (1992). 'Variations in breast cancer management between a teaching and non-teaching district hospital', European Journal of Cancer, 28, (a), p.1945-1950.

Beauchamp, T. & Childress, F. (2001) Principles of biomedical ethics (5<sup>th</sup> ed). Oxford: University Press.

Beaver, K. Luker, K. & Woods, S. (1999) 'Conducting research with the terminally ill: challenges and considerations'. International Journal of Palliative Nursing 5(1), p.13-18.

Beaver, K. Tysver-Robinson, D. Campbell, D. Twoney, M. Williamson, S. Hindley, A. Susnerwala, S. Dunn, G. & Luker, K. (2009) 'Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial'. BMJ [online] 338 (a3147) available from: <http://gateway.ovid.com> [Accessed 31<sup>st</sup> October 2009]

Beck, L. Trombetta, W. & Share, S. (1986) 'Using focus group sessions before decisions are made'. North Carolina Medical Journal, 47, (2), p.73-74.

Benner, P. (1984) 'From novice to expert: excellence and power in clinical practice. New York: Addison-Wesley.

Berger, A. (2002) 'Arrogance among Physicians' Academic Medicine 77, (2), p. 145-147.

Blanks, R.G. Moss, S.M. McGaham, C.E. Quinn, M.J. & Babb, P.J. (2000) 'Effect of NHS Breast Screening Programme on mortality from breast cancer in England and Wales 1990-1998. Comparison of observed with predicted mortality. B.M.J., 321, (7262), p.665-669.

Block, L.G. & Williams, P. (2002) 'Undoing the effects of seizing and freezing: decreasing defensive processing of personally relevant messages'. Journal of Applied Social Psychology. 32, p.803-833

Bonadonna, G. Moliterni, A. Zambetti, M. Daidone, M.G. Pilotti, S. Gianni, L. & Valagussa, P. (2005) '30 years' follow-up of randomised studies of adjuvant CMF in operable breast cancer: cohort study. B.M.J..330, (7485), p.217-20.

Boudioni, M. Mossman, J. Jones, A. McPherson, K.& Leydon, G. (1998) 'Celebrity's death from cancer resulted in increase call to cancer BACUP'. B.M.J..317, (7164), p.1016.

Botti, M. Endacott, R. Watts, R. Cairns, J. & Lewis, K. ( 2006) 'Barriers in Providing psychosocial support for patients with cancer'. Cancer Nursing. 29, (4), p.309-316.

Bower, J.E. Ganz, P.A. Desmond, K.A. Rowland, J.H. Meyerowitz ,B.E. & Berlin, T.R. (2000) 'Fatigue in breast cancer survivors: occurrence, correlates and impact on quality of life'. Journal of Clinical Oncology. 18, (4), p.743-753.

Brada, M. (1995) 'Is there a need to follow-up cancer patients?' European Journal of Cancer. 31A, (5), p.655-657.

Bradshaw, P.(2001) 'Politics, power and control in the British National Health Service – will anything really change?' Journal of Nursing Management. 9, (6), p311 – 313.

Breast Cancer Care Newsletter. Autumn. (2001).

Brennan, M. (2004) 'Social factors are important to patient care'. Nursing Standard 19, (5), p.25.

Broeckel, J.A. Thors, C.L. Jacobsen, P.B. Small, M. & Cox, C.E. (2002)'Sexual functioning in long term breast cancer survivors treated with adjuvant chemotherapy'. Breast Cancer Research and Treatment. 75, (3), p.241-248.

Brooks, I. & Brown, R.B. (2002) 'The role of ritualistic ceremonial in removing barriers between subcultures in the National Health Service' Journal of Advanced Nursing. 38, (4), p.341-352.

Brooks I. & Bate S.P. (1994) 'The problems of effecting change within the British civil service: a cultural perspective'. British Journal of Management 5, p.177–190.

Browall, M. Gaston-Johansson, F. & Danielson, E. (2006) 'Postmenopausal women with breast cancer: Their experience of the chemotherapy treatment period'. Cancer Nursing. 29, (1), p34 - 42.

Brown, S. & Lent, R. (2000) Handbook of counselling psychology. New York: John Wiley and Sons.

Broyard, A. (1992) Intoxicated by My Illness and Other Writings on Life and Death. New York: Fawcett Columbine.

Bryman, A. (2001) Social research methods. Oxford University Press : Oxford.

Bryman, A. & Cramer, D. (2004) 'Quantitative data analysis with SPSS 12 and 13: a guide for social scientists'. London: Routledge.

Bulmer, C. (1998) 'Clinical decisions: defining meaning through focus groups'. Nursing Standard. 12, (20), p.34-36.

Bultz, B.D. Specia, M. Brasher, P.M. Geggie, P.H. & Page, S. (2000) 'A randomised controlled trial of a brief psycho educational support group for partners of early stage breast cancer patients' Psycho-oncology 9, p.303-313.

Bultz, B.D. & Carlson, L. E. (2005) 'The emotional distress; the sixth vital sign in cancer care' Journal of Clinical Oncology. 23, (26), p.6440 - 6441.

Bunkers, S. Petardi, L. Pilkington, F. & Walls, P. (1996) 'Challenging the myths surrounding qualitative research in nursing'. Nursing Science Quarterly. 9, (1), p33-37.

Burgess, C. Ramirez, A. Cornelius, V. Love, S. Graham, J. & Richards M. (2005) 'Depression, anxiety, or both in women with early breast cancer: five year observational cohort study'. B.M.J. 330, (7002), p.1136.

Burgess, R.G. (1984) In the field London : Allen and Unwin.

Burkitt-Wright, E. Holcombe, C & Salmon, P. (2004) 'Doctors communication of trust, care and respect: author's reply'. B.M.J. 328, (7451), p.1319.

Burnet, K. Chapman, D. Wishart, G. & Purushotham, A. (2004) 'Nurse specialist in breast care: a developing role. Nursing Standard 18, (45), p.38-42.

Burns, N. & Grove, S. (2005) The practice of nursing research. conduct, critique & utilization. (5<sup>th</sup> ed) Philadelphia: Saunders.

Butler, S. (1996) 'Child protection or professional self-preservation by the baby nurses? Public Health Nurses and Child Protection in Ireland'. Social Science and Medicine. 43 p303-314.

Cahill, J. (1998) 'Patient participation – a review of the literature', Journal of Clinical Nursing. 7, (2), p.119-128.

Caldwell, K. Coleman, K. & Holmshaw, J. (2008) 'Involving older service consumers in health research: practicalities and processes'. Research, Policy and Planning 26, (2) p113-112.

Calinas-Correia, J. (2001) 'What power for whom?' B.M.J. [online]. 323, (7310). Available from <http://www.bmj.com/cqi> [Accessed October 9<sup>th</sup> 2007].

Camidge, R. Walker, A Oliver, J. Nussey, F. Maxwell, S. Jodrell, D. & Webb, D.(2005) Prognosis without treatment as a modifier in health economic assessments B.M.J. 330, (7504), p.1382 – 1384.

Campbell, D. MacLeod, U. & Weller, D. (2002) 'Primary care oncology: essential if high quality cancer care is to be achieved for all' Family Practice. 19, (6), p577-578.

Cancer Research Campaign (1997) Breast Cancer: Fact Sheet, Birmingham: Institute of Cancer Studies at University of Birmingham/ CRC.

Cancer Research U.K. [Home page of Cancer research U.K.]. [Online]. December 2009. Available from: <http://www.cancerresearchuk.org/statistics> [Accessed 15th December 2009].

Cancer Service Collaborative Improvement Partnership (CSC- 'IP') (2006) 'The Challenge of Implementing Sustainable Improvement in Cancer Services in association with DOH Cancer Waits Project. [www.cancerimprovement.nhs.uk](http://www.cancerimprovement.nhs.uk)

Canter, R. (2001) 'Patients and Medical Power' B.M.J. 323, (7310), p. 414.

Castledine, G. (1995) 'Defining specialist nursing ' British Journal of Nursing 4, (5), p.264-265.

Castledine, G. (1996) 'Clarifying and defining nursing role development'. British Journal of Nursing. 5, p.1338 -1338.

Carver, C. & Antoni, M. (2004)' Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5-8 years after diagnosis' Health Psychology. 23, (6), p.595-598.

Chamberlain - Wilmoth, M. Tulman, L. Coleman, E.A. Stewart, C.B. & Samarel, N. (2006) 'Women's perceptions of the effectiveness of telephone support and education on their adjustment to breast cancer'. Oncology Nursing Forum. 33, (1), p.138-144.

Charmaz, K. (2000) 'Grounded theory: objectivist and constructivist methods'. In Denzin, N. & Lincoln, Y. (2<sup>nd</sup> eds.). Handbook of Qualitative Research California Thousand Oak, p. 509-536.

Cheson, B. Lacerna, L. Leyland-Jones, B. Sarosy, G. & Wittes, R.E. (1989) 'Autologous bone marrow transplantation: current status and future directions'. Annals of International Medicine. 110, p. 51-65.

Chinthapalli, R. (2001) 'Power and Duty'. B.M.J. [online]. 323, (7310). Available from <http://www.bmj.com/cgi> [Accessed September 9th 2007].

Chochinov, H. Hact, T. Hassard, T. Kristjanson, L. McClement, S. & Hartos, M. (2002) 'Dignity in the terminally ill: A Cross Sectional, Cohort Study'. Lancet. 360 p.2026-2030.

Chochinov, H. (2007) 'Dignity and The Essence of Medicine: The A,B,C,D of dignity conserving care'. B.M.J. 337, (7612), p.184-187.

Churn, M. & Kelly, V. (2001) 'Outpatient follow-up after treatment for early breast cancer: Updated results after 5 years.' Clinical Oncology. 13, p.187-194.

Clarke, A. (1999) 'Focus group interviews in health care research' Professional Nurse. 14 (6) p 3395-397.

Clark, J. Wray N. & Ashton C. (2001) 'Living with treatment decisions: regrets and quality of life among men treated for metastatic prostate cancer' Journal of Clinical Oncology 19, (1), p72-80.

Cleary, M. & Warren, R. (1998), 'An exploratory investigation into women's experience in a mixed sex psychiatric admission unit.' Australian and New Zealand Journal of Mental Health Nursing 7, (1), p. 33-40.

Coghlan, D. & Brannick, T. (2001) 'Doing action research in your own organisation'. (2<sup>nd</sup> ed). London: Sage.

Coghlan, D. and Casey, M. (2001) 'Action research from the insider: Issues and challenges in doing action research in your own hospital.' Journal of Advanced Nursing [online] 35, (5) p.674-682. Available from: <http://gateway.ovid.com> [Accessed September 2008].

Coiera, E. (1996) 'The internet's challenge to health care provision'. B.M.J.312, (7022), p.3-4.

Coleman, P. Gatta, G.. Verdecchia, A. . Estève, J. . Sant, M. Storm, H. . Allemani, C. Ciccolallo, L. Santaquilani, M. Berrino F. & the Eurocare Working Group (2003) 'EUROCORE – 3 summary; cancer survival in Europe at the end of the 20<sup>th</sup> century' Annals of Oncology. (Supplement 5), p.128-149.

Commission for Health Improvement/Audit Commission (2001) (CHI/AC) 'National Service Framework Assessment No.1 NHS Cancer Care in England and Wales'. London.

Coombes, R.C. Hall, E. Gibson, L. Paridaens, R. Jassem, J. Delozier, T. Jones, S. Alvarez, I. Bertelli, G. Ortmann, O. Coates, A. Bajetta, E. Dodwell, D. Coleman, R. Fallowfield, L. Mickiewicz, E. Andersen, J. Lonning, P. Cocconi, G. Stewart, A. Stuart, N.



Snowdon, C. Carpentieri, M. Massimini, G. & Bliss, J. (2004) 'A randomised trial of Exemestane after two to three years of Tamoxifen therapy in postmenopausal women with primary breast cancer'. New England Journal of Medicine. 350, (11), p.1081-1092.

Cooper, N. & Westlake, S. (2008) 'Cancer incidence and mortality: trends in the U.K. and constituent countries, 1993 to 2004'. Statistics Quarterly. 38, p.33-46.

Corner, J. Haviland, J. Wells, M. Salmon, E. Normand, C. Brada, M. O'Brien, M. & Smith, I. (2002) 'Nurse led follow-up and conventional medical follow-up in the management of patients with lung cancer: randomised trial'. B.M.J. 325, (7373), p.1145 – 1147.

Costanzo, E.S. Lutgendorf, S.K. Mattes, M.L. Trehan, S. Robinson, C.B. Tewfik, F. & Roman, S.L. (2007) 'Adjusting to life after treatment: distress and quality of life following treatment for breast cancer'. British Journal of Cancer [online] 97 Available from <http://www.nature.com/bjc/journal/v97/n12/abs/6604091a.html> [Accessed 12th May 2009].

Coulter, A. (1998) 'Evidence based patient information matrix'. B.M.J. 317, (7153), p.225-226.

Cowles, K. V. (1988) 'Issues in qualitative research in sensitive topics'. Western Journal of Nursing Research. 10,p.163 -179.

Cox, K. & E, Wilson. (2003) 'Follow-up for people with cancer: nurse led services and telephone interventions' Journal of Advanced Nursing 43, (1), p.51-61.

Cox, K. Wilson, E, Heath, L. Collier, J. Jones, L. & Johnston, I. (2006) 'Preferences for Follow-up After Treatment for Lung Cancer: Assessing the Nurse-led Option' Cancer Nursing. Volume 29(3), p.176-187.

CQuINS. [Homepage of the online tool for the quality improvement of cancer care through self assessment and peer review]. [Online]. No Date. Available from <http://www.cquinns.nhs.uk> [Accessed 19 July 2008].

Curry, T. (2005) 'Payment by Results' Nursing Management. 12, (3), p.16-19.

Cuzick, J. (2001) 'A brief review of the international breast cancer intervention study (IBIS), the current breast cancer prevention trials and proposals for the future'. Annals of the New York Academy of Sciences. 949, (1) p.123-133.

Daley, A. Mutrie, N. Crank, H. Coleman, R. & Saxton, J. (2004) 'Exercise therapy in women who have had breast cancer: design of the Sheffield women's exercise and well-being project'. Health Education Research. 19, (6), p.686-697.

Darzi, A. (2007) 'Healthcare for London. A framework for action'.  
[www.healthcareforlondon.nhs.uk](http://www.healthcareforlondon.nhs.uk)

Davies, E. A. Hall, S. M. Clarke, C.RR.A. Bannon, M.P. & Hopkins A.P. (1998) 'Do research interviews cause distress or interfere in management?' Journal of the Royal College of Physicians 32,(5),p.406-411.

Day, M. (2006) 'England's cancer plan needs an overhaul, think tank says' B.M.J. 333, (7566), p.462.

Day, M. (2007) 'Experts dispute claims of poor cancer survival in UK'. B.M.J. 334, (7602), p.1021.

Dealey, C. (2005) 'The factors that influence patient's choice of hospital and treatment'. British Journal of Nursing. 14, (10), p. 576-579.

de Bock, G.H. Bonnema, J. van Der Hage, J. Kievit, J. & van de Velde C.J.H. (2004) 'Effectiveness of routine visits and routine tests in detecting isolated loco regional recurrences after treatment for early stage invasive breast cancer: A meta-analysis and systematic review'. Journal of Clinical Oncology. 22, (19), p. 4010- 4018.

de Bock, G.H. Bonnema, J. Zwaan R.E. van de Velde C.J. Kievitt J. & Stiggelbout, A.M. (2004a) 'Patient's needs and preferences in routine follow-up after treatment for breast cancer'. British Journal of Cancer. 90, (6), p.1144-1150.

De Marco, R. Piccard,C. & Agretelis, J. (2004) 'Nurse experiences as cancer survivors: part 1-personal'. Oncology Nurse Forum 31, (3), p.523-530.

Denzin, N. (1989) 'The research act: A theoretical introduction to sociological methods'. (3<sup>rd</sup> ed). Englewood Cliffs NJ: Prentice – Hall .

Department of Health (1986) Breast screening report to the health ministers of England, Wales, Scotland and Northern Ireland. [The Forrest Report] London: HMSO.

Department of Health. (1989). Working for patients: The Health Service caring for the 1990s London: HMSO.

Department of Health. (1991). The Patients Charter. London: HMSO.

Department of Health. (1995). Expert advisory group on cancer. A policy framework for commissioning cancer services. London: HMSO.

Department of Health. (1996). Cancer guidance subgroup of the clinical outcome group. Guidance for purchasers: improving outcomes in breast cancer. London: HMSO.

Department of Health. (1997). The new NHS: modern, dependable London: HMSO

Department of Health (1999) 'Making a difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare'. London: HMSO

Department of Health. (1999a). Patient and Public involvement in the new NHS London: HMSO.

Department of Health. (2000). The Cancer Plan London: HMSO.

Department of Health. (2000a). The NHS Plan ; a plan for Investment, a plan for reform. London: HMSO.

Department of Health. (2000b). The nursing contribution to cancer care. London: HMSO.

Department of Health. (2000c). The cancer information strategy. London: HMSO.

Department of Health. (2001). The essence of care: patient-focused benchmarks for clinical governance. London: HMSO.

Department of Health. (2002). 'Guidance of working patterns for junior doctors' London: HMSO.

Department of Health. (2003). Reforming financial flows: introducing payment by results. London: HMSO.

Department of Health. (2005). Cancer service collaborative 'Improvement partnership' applying high impact changes to cancer care. Excellence in cancer care. London: HMSO.

Department of Health. (2005)a. 'Your health, your care, your say'. London: HMSO.

Department of Health (2005b) Tackling cancer: improving the patient journey London: HMSO. ISBN 0 102932271.

Department of Health (2006) "A stronger local voice: a framework for creating a stronger local voice in the development of health and social services". London: HMSO.

Department of Health (2006a) 'Modernising nursing careers – setting the direction' London: HMSO.

Department of Health (2006b) Partnership for older people projects: making the shift to prevention. London: HMSO.

Department of Health (2007) Cancer reform strategy – executive summary. London: HMSO

Department of Health (2007 annex c) Cancer Reform Strategy - Breast Cancer 2012

Dewar, J. (1995) 'Follow-up in breast cancer: a suitable case for reappraisal'. B.M.J. 310, p.685-686.

Dickenson H. O. (2000) 'Cancer trends in England and Wales good data and analysis are vital to improving survival'. B.M.J. 320, (7239), p.884-885.

Dingwall, R. (2001) 'Is patient power such a good idea in an N.H.S.?' B.M.J. [online]. 323, (7310). Available from <http://www.bmj.com/cgi> Accessed 15th August 2007].

Dinsdale, P. & Waters, A. (2006) 'Because we're worth it' Nursing Standard 21, (12), 29 pp 20-22.

DIPEX.org [Homepage of DIPEX.org]. [online]. 9July 2007. Available from <http://www.dipex.org> [Accessed 12 July 2008].

Dirksen, S. (2000) 'Predicting well-being among breast cancer survivors'. Journal of Advanced Nursing. 32, (4), p.937-943.

Dixon, J. (2008) 'Darzi's review of quality of care in the NHS' B.M.J. 336, (7649), p.844-845.

Dixon, J.M. & Montgomery, D. (2008) 'Follow-up after breast cancer' B.M.J. [online]. 336, Available from <http://www.bmj.com>. [Accessed 23rd July 2008]

Donnelly, J. Mack, P. & Donaldson, L.A. (2001) 'Follow-up of breast cancer: time for a new approach'. International Journal of Clinical Practice. 55 (7) p.431-433.

Donnelly, P. Hiller, L. Bathers, S. Bowden, C. & Coleman, R. (2007) 'Questioning specialists' attitudes to breast cancer follow-up in primary care' Annals of Oncology Advance Access [online]. Available from <http://annonc.oxfordjournals.org/cgi/content/abstract/> [Accessed 12<sup>th</sup> May 2007]

Donnelly, P. K. Hiller, L. & Dunn, J.A. (2008) 'Need for the iBreast trial – risk adjusted breast cancer follow-up trial'. B.M.J. 336, (7642), p. 461

Dowling, M. (2006) 'The sociology of intimacy in the nurse-patient relationship' Nursing Standard. 20, (23), p.48-54.

Dowling, M. (2006a) 'Approaches to reflexivity in qualitative research.' Nurse Researcher 13, (4). p.7-21.

Doyal, L. & Gough, I. (1991) A Theory of Human Need. Macmillan. Basinstoke.

Duffy, C. Allen, S. & Clark, M. (2005) 'Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy' Journal of Clinical Oncology. 23, (4), p.766-773.

Duffy, M. (1985) 'Designing nursing research: the qualitative quantitative debate', Journal of Advanced Nursing, 10, (3), p225-232.

Duggleby, W. (2005) 'What about Focus Group Interactions data?' Qualitative Health Research. 15 (6) p.832-840.

Dunn, B. K. Wickerham, D.L. & Ford L.G. (2005) 'Prevention of hormone related cancers : Breast Cancers'. Journal of Clinical Oncology. 23, (2), p.357-367.

Earle, C.C. & Neveille, B.A. (2004) 'Under use of necessary care among cancer survivors'. Cancer 101, p.1712-1719.

Early Breast Cancer Trials Collaborative Group. (1998) 'Polychemotherapy for early breast cancer: an overview of randomised trials'. Lancet 352 ( 930) p.942.

Early Breast Cancer Trials Collaborative Group. (2005) 'Long running study shows fifteen year survival gains in early breast cancer'. The Lancet 365 (9472) p.1687-1717).

Earnshaw, J.J. & Stephenson, Y. (1997) 'First two years of a follow - up breast clinic led by a nurse practitioner'. Journal of the Royal Society of Medicine. 90 p258-259.

Earnshaw, A. & Reilly, P. (2001) 'Patients, doctors and power.' B.M.J. [online]. 323 (7310). Available from <http://www.bmj.com/cgi>



Edwards, C. Staniszweska, S. & Crichton, N. (2004) 'Investigation of the ways in which patients' reports of their satisfaction with healthcare are constructed'. Sociology of Health and Illness 26, (2), p159-183.

Ehrenberg, A. Ehnfors, M. & Thorell-Ekstrand, I (1996) 'Nursing document in patient records; experience of the use of the VIPS model'. Journal of Advanced Nursing. 24 (4), 853-867.

Eide, P. & Kahn, D. (2008) 'Ethical issues in the qualitative researcher – participant relationship.' Nursing Ethics [online] 15, (2). Available from: <http://nej.sagepub.com> [Accessed June 2009].

Elder, G. (1997) 'The alienated: growing older today' London: Writers' and Readers' Publishing Co-operative.

Elmberger, E. Bolund, C. Magnusson, A. Lütze K. & Anderson, B. (2008) 'Being a mother with cancer: achieving a sense of balance in the transition process'. Cancer Nursing. 31, (1), p58-66.

Elwyn, G. Buetow, S. Hibbard, J. & Wensing, M. (2007) 'Respecting the subjective: quality measurement from the patient's perspective' B.M.J. 335, (7628), p.1021-1022.

Entwhistle, V. Renfrew, M Yearley, S. Forrester, J. & Lamont, T. (1998) 'Lay perspectives: advantages for health research' B.M.J. 316, (7129), p.463-466.

Ersser, S. (1996) 'Ethnography in clinical situations: An ethical appraisal'. In L. DeRaeve (ed.). Nursing research : An ethical and legal appraisal London: Bailliere Tindall, p. 42-56.

Eurocare [Homepage of **E**uropean **c**ancer **r**egistry base]. [online]. No date Available from: <http://www.eurocare.it/> [Accessed 15 December 2009].

Faithfull, S. (1999) 'Randomised trial, a method of comparisons: a study of supportive care in radiotherapy nursing'. European Journal Oncology Nurse. 3, (3), p.176-184.

Faithfull, S, Corner, J, Meyer, L, Huddart, R, & Dearnaley, D. (2001) Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy. British Journal of Cancer. 85, (12), p.1853-1864.

Fallowfield, L.J. Hall, A. Maguire, P. Baum, M. & A'Hern, R.P. (1994) 'Psychological effects of being offered choice of surgery for breast cancer. B.M.J. 309, p.448-451.

Fawzy, F.I. (1999) 'Psychosocial interventions for patients with cancer: what works and what doesn't' European Journal of Cancer. 35, (11), p.1559-64.

Felder, B.E. (2004) 'Hope and coping in patients with cancer diagnoses' Cancer Nursing. 27, (4), p320-324.

Fenton, K. (2005) 'Editorial' Nursing Management. 12, (2), 3, p 3.

Ferrell BR (1996) 'The quality of life: 1.525 voices of cancer'. Oncology Nurse Forum. 23, (6), p.907-916.

Ferrell, B.R. Grant, M.M. Funk, B.M. Garcia, N. Otis-Green, S. & Schaffner, N. (1996a) 'Quality of life in breast cancer. Cancer Practise 4, (6), p.331-340.

Fielding, N.G. & Fielding, J.L. (1986) 'Linking data: The articulation of qualitative and quantitative methods in social research'. Beverly Hills Sage.

Fielding N., 1993. 'Qualitative interviewing'. In: N. Gilbert (ed). Researching Social Life Sage: London.

Fleissig, A. Jenkins, V. Catt, S. Fallowfield, L. (2006) 'Multidisciplinary teams in cancer care: are they effective in the UK?' The Lancet Oncology 7 (11) p.935-943.

Fontes, P. & Thompson, W. (1999) 'Where are we going? Stem cell technology' B.M.J. 319, p.1308-1318.

Ford, S. Fallowfield, L. & Lewis, S. (1995) 'No News is not good news: information preferences of patients with cancer'. Psycho-oncology 95, (4), p.197-202.

Foucault M (1982) 'The subject and power' in H.L. Dreyfrus and P. Rainbow (eds) Beyond Structuralism and Hermeneutics. Brighton: Harvester Press.

Frankel, R. & Quill, T. (2005) 'Integrating biopsychosocial and relationship-centred care into mainstream medical practice: a challenge that continues to produce positive results'. Families, Systems and Health. 23, (4), p.413-421.

Fredette, S. (1995) 'Breast cancer survivors: concerns and coping'. Cancer Nursing. 18, (1), p.35-46.

Friedenberg, R. (2003) 'Rationing health care: changing the patterns of health care.' Radiology. 227, p.5-8.

Fudge, N. Wolfe, C.D.A. & McKevitt, C. (2008) 'Assessing the promise of user involvement in health service development: ethnographic study.' BMJ. [online] 336, (7639) Available from : <http://www.bmj.com/cgi/content/abstract/336/7639/313> [Accessed 25th April 2009].

Gadamer, H.G. (1976) Philosophical Hermeneutics. London: University of California Press.

Gannon, C. (2005) 'Will the lead clinician please stand up?' B.M.J. 330, (7493), p. 737.

Ganz, P. Desmond, K. Belin, T. Meyerowitz, B. & Roland, J. (1999) 'Predictors of sexual health in women after a breast cancer diagnosis'. Journal of Clinical Oncology 17, (8), p. 2371-2800.

Gasson, S. (2004) 'Rigour in grounded theory research: an interpretative on generating theory from qualitative field studies' in M. Whitman & A. Woszczynski (eds.). The handbook of information systems research London : Idea Group p.79 -102.

Garvican, L. Grimsey, E. Littlejohns, P. Lowndes, S. & Sacks, N. (1998) 'Satisfaction with clinical nurse specialists in a breast care clinic: questionnaire survey'. B.M.J. 316, (7136), p. 976-977.

Gawlinski, A. & Kern, L.S. (1994) 'The clinical nurse specialist in critical care' W.B. Saunders.

Gee, K. (1995) 'Competency through being the enemy within?' British Journal of Nursing. 4, (11), p.637-640.

Gigerenzer, G. & Edwards, A. (2003) 'Simple tools for understanding risks; from innumeracy to insight. B.M.J. 327, (7417),p.741-744.

Gilbert-Welch, H. & Mogielnicki, J. (2002) 'Presumed benefit: Lessons from the American experience with marrow transplantation for breast cancer'. BMJ. 324, (7345), p.1088-1092.

Gibson, V. (1996) 'The problems of researching sensitive topics in health care'. Nurse Researcher. 4, (2), p.65-74.

GIVIO Investigators (1994) 'Impact of follow-up testing on survival and health related quality of life in breast cancer patients' Journal of American the American Medical Association. 271, (20), p. 1587-1592.

Glaser, B. & Strauss, A.L. (1967) The discovery of grounded theory: strategies for qualitative research. Chicago. Aldine.

Goodwin, L. & Goodwin, W.L. (1984) 'Qualitative versus' quantitative research or qualitative and quantitative research?' Nursing Research 33,(6), p.378-380.

Goodwin, P.A., Leszcz, M., Ennis, M. Koopmans, J. Vincent, ,L. Guther, H. Drysdale, E. Hundlesby, M. Chochinov, H. Nararro, M Specia, M. & Hunter, J (2001) 'The effect of

psychosocial support on survival in metastatic breast cancer'. New England Journal of Medicine 345. (24). p.1719-1726.

Gott, M. Stevens T. Small, N. Hjelmeland & Ahmedzai, S. H. (2000) 'User involvement in cancer care exclusion and empowerment' Policy Press Bristol.

Gotzsche, P.C. & Olsen, O. (2000) 'Is screening for breast cancer with mammography justifiable?' The Lancet 355, (9205), p.129-134.

Gray, R. Fitch, M. Davis, C. & Phillips, C. (1997) 'A qualitative study of breast cancer self-help groups'. Psycho-Oncology 6 (4), p. 279-89.

Grogan, M. Rangan, A. Gebiski,V. & Boyages, J. (2002) 'The value of follow-up of patients with early breast cancer treated with conservative surgery and radiation therapy'. Breast 11, p.163-169.

Grunfeld, E. Fitzpatrick, R. Mant, D. & Vessey, M. (1995) 'Specialist and general practice views on routine follow-up of breast cancer patients in general practice'. Family Practice 12, (1), p.60-65.

Grunfeld, E. Fitzpatrick, R. Mant, D. Yudkin, P. Adewuyi-Dalton, R.Stewart, J. Cole, D. & Vessey, M. (1996) 'Routine follow-up of breast cancer in primary care: a randomised trial. B.M.J. 313, (7058), p.665-669.

Grunfeld, E. Fitzpatrick, R. Mant, D. Yudkin, P. Adewuyi-Dalton, R.Stewart, J. Cole, D. & Vessey, M. (1999) 'Comparison of breast cancer patient satisfaction with follow-up in

primary care versus specialist care: results from a randomised controlled trial'. British Journal of General Practice. 49, p.705-710.

Grunfeld, E. Noorani, H. McGahan, L. Paszat, D. Coyle, D. van Walraven, C. Joyce, J. & Sawka, C. (2002) 'Surveillance mammography after treatment of primary breast cancer; A systematic review. The Breast 11, (3), p.228-235.

Grunfeld, E. Levine, M.N. Julian, J.A. Coyle, D. Szechtman, B. Mirsky, D. Shailendara, V. Dent, S. Sawka, C. Prichard, K.I. Ginsburg, D. Wood, M. & Whelan, T. (2006) 'Randomised trial of long term follow-up for early stage breast cancer: A comparison of family physician versus specialist care ' Journal of Clinical Oncology 24, (6), p.848-855.

Gulliford, T. Opomu, M. Wilson, M. Hanham, I. & Epstein, R. (1997) 'Popularity of less frequent follow up for breast cancer in randomised control study: Initial findings from hotline study.' B.M.J. 314, (7075), p.174.

Haggerty, J. L. Reid, R. J. Freeman, G. K. Starfield, B. H. Adair, C. & McKendry, R. (2003)' Continuity of care: a multidisciplinary review B.M.J. 327, (7425), p.1219-1221.

Halcombe, E. J. & Andrew, S. (2005) 'Triangulation as a method for contemporary nursing research'. Nurse Researcher 13, (2), p.71-82.

Ham C. (2005) 'From targets to standards: but not just yet' B.M.J. 330, (7483), p.106-107.

Hammond, C. Chase, J. & Hogbin, B. (1995) 'A unique service'. Nursing Times 91, (30), p.28-29.

Harris, J. Lippman, M. Morrow, M. & Osborne, C. (2000) Diseases of the breast. (3<sup>rd</sup> ed). Philadelphia: Lippincott.

Hauser M., (1972) The Economist of medical care. London: Allen and Urwin.

Hayes, D.F. (2007) 'Follow-up patients with early breast cancer'. New England Journal of Medicine 356, (21), p.2505-2513

Haylock, P.J. (2006) 'The shifting paradigm of cancer care.' American Journal of Nursing 106, (3 Suppl), p.16-19

Haylock, P. Mitchell, S. Cox, T. Temple, S. V. & Curtiss C (2007) 'The cancer survivor's prescription for living.' American Journal of Nursing 107, (4), p.58-70.

Health and Social Care Act (2001) Office of Public Sector Information London.

Hehir, B. (2005) 'Who's the boss?' Nursing Standard 19. (22), p.22-23.

Helgeson V,S, Cohen S., Schulz R., & Yasko J (2000) 'Group support interventions for women with breast cancer: who benefits from what ?' Health Psychology 19, p107-114.

Helman, C. (1981) 'Disease versus illness in general practice'. Journal of The Royal College of General Practitioners. 31, p. 548 -552.

Herth, K. (2001) 'Development and implementation of a hope intervention programme'. Oncology Nurse Forum.28, (6), p.1009-1016.



Hewitt-Taylor J (2004) 'Challenging the balance of power: patient empowerment' Nursing Standard 18, (22), p.33-37.

Hewitt, M. Greenfield, S. & Stovall, E. (2006) editors 'From cancer patient to cancer survivor: lost in transition'. Washington D.C. Institute of Medicine National Academics Press.

Hirschman, A.O. (1970) 'Exit voice and loyalty: responses to decline in firms, organisations and states'. Cambridge: Harvard University Press.

Hisrich, R. & Peters, M. (1982) 'Focus groups: an innovative marketing research technique'. Hospital and Health Service Administration. 5, p.8-21.

Hitchen, L. (2007) 'Patients with cancer could spend less time in hospital, says tsar' B.M.J. 334, (7603), p.1079.

Hopkins Tanne, J. (2003) 'Stem cell transplants are not helpful in breast cancer, studies say.' B.M.J. 327, (7406), p.68

Hugman, R. (1991) 'Power in caring professions' London: Macmillan

Humphries, D. (1994) 'The clinical nurse specialist: issues in practice'. Macmillan Basingstoke.

Hunter. D, (1996) .Rationing and evidence-based medicine.. Journal of Evaluation in Clinical Practice. 2. p.5-8.

Hussain, S.T. Gui, G.P.H. Lee, K.S. Plowman, P.N. Gilmore, O.J.A. & Allum W.H. (1995) 'Detection of Loco-regional Recurrence after Breast Conserving Surgery and Radiotherapy'. Journal of the Royal College of Surgery Edinburgh. 40, p.163-166.

I.B.C.S.G. [Home page of International Breast Cancer Study Group]. [Online].8 May 2008.

Available from:

[http://www.ibcsg.org/Public/Health\\_Professionals/Open\\_Trials/IBCSG\\_31-03/Pages/IBCSG31-03\(IBISII\).aspx](http://www.ibcsg.org/Public/Health_Professionals/Open_Trials/IBCSG_31-03/Pages/IBCSG31-03(IBISII).aspx) [Accessed 6. June 2008].

INVOLVE (2006) 'Guide to reimbursing and paying members of the public actively involved in research: for researchers and research commissioners (who may also be service consumers). Available on line at

[http://www.invo.org.uk/pdfs/Payment\\_Guidefinal240806.pdf](http://www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf) [Accessed 15<sup>th</sup> August 2009].

Jack, W.J.L. Kerr, G.R. & Kunkler I.H. (1989) 'Long term follow-up after breast conservation: the Edinburgh experience'. Breast 7, p.80-84.

Jacobsen, P.B. (2005) 'Screening for psychological distress in ambulatory cancer patient' Cancer 103, (7), p. 1494-502.

James, N.D. Guerrero, D. & Brada, M. (1994) 'Who should follow-up cancer patients? Nurse specialist-based outpatient care and the introduction of the phone clinic system'. Clinical Oncology 6, p.283-287.

Jefford, M. & Tattersall, M.H.N. (2002) 'Informing and involving cancer patients in their own care' Lancet Oncology 3, (10), p.629-637.

Jensen, K. Back-Pettersson, S. & Segesten, K. (2000) The meaning of "not giving in": lived experiences among women with breast cancer. Cancer Nursing. 23, (1), p.6-11.

Jick, T. (1979) 'Mixing qualitative and quantitative methods: triangulation in action'. Administrative Science Quartely. 24, p.602-611.

Johnson, B.M. & Plant, H. (1996) 'Collecting data from people with cancer and their families: What are the implications?' In L. De Raeve (ed). Nursing research: An ethical and legal appraisal London: Bailliere Tindall, p.85-100.

Johnson, M. (1999) 'Observations on positivism and pseudoscience in qualitative nursing research'. Journal of Advanced Nursing 30, (1), p.67-73.

Johnson, J. (2000) 'An Overview of Psychosocial support services: resources for healing'. Cancer Nursing 23, (4), p.310-313.

Johnson, B. & Macleod Clarke, J (2003) 'Collecting sensitive data: The impact on researchers'. Qualitative Health Research. [online] 13, (3), p.421-434. Available from <http://qhr.sagepub.com> at Middlesex University [November 23 2008].

Jones, A.L (2005) 'Reduction in mortality from breast cancer' B.M.J. 330, (7485), p. 205 – 206.

Jones, C. & Lyons, C. (2004) 'Case study design? Method? Or comprehensive strategy'. Nurse Researcher 11, (3), p.70-76.

Jones, R.B. Pearson, J. Cawsey, A.J. Bental, D. Barrett, A. White, J. White, C.A. & Gilmour, W.H. (2006) 'Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial' B.M.J. 332, (7547,) p.942-948.

Jones, R. Latinovic, R. Charlton, J. & Gulliford, M. C. (2007) 'Alarm symptoms in early diagnosis of cancer in primary care: cohort study using General Practice research database'. B.M.J. 334, (7602), p.1040.

Jootun, D. McGhee, G. & Marland, G. (2009) 'Reflexivity: promoting rigour in qualitative research'. Nursing Standard. 23, (23), p. 42-46.

Karani, D. & Wiltshaw, E. (1986) 'How well informed?' Nursing Times 9, (5), p.238-242.

Keeling, A.W. & Dennison, P.D. (1995) 'Nurse-initiated telephone follow-up after acute myocardial infarction: a pilot study'. Heart Lung 24, (1), p.45-49.

Kelly, D. (2004) 'Patients with colorectal cancer expressed a loss of adulthood related to a loss of professional and sexual identity, dignity, privacy, independence and ability to socialise'. Evidence Based Nursing. 7, p.126.

Kennedy, I. (2003) 'Patients are experts in their own field' B.M.J. 326, (7402), p.1276-1277.

Kerssens J, Benzing J, & Andela M.(1997) 'Patient preference for genders of health professionals'. Social Science Medicine 44, p.1531-1540.

Khatcheressian, J. Wolff, A. Smith, T. Grunfeld, E. Muss, H. Vogel, V. Halberg, F. Somerfield, M. & Davidson, N. (2006) 'American society of clinical oncology 2006 update of the breast cancer follow-up and management guidelines in the adjuvant setting'. American Society of Clinical Oncology 24, (31), p.5091-5097.

Khatcheressian, J. & Smith, T. (2006) 'Randomised trial of long-term follow-up for early breast cancer: a comparison of family physician versus specialist care'. Journal of Clinical Oncology 24, (6), p.835-837.

Kimmel, A. (1988) Ethics and Values in Applied Social Research. London: Sage.

Kingsmore, D.B. Hole, D. Gillis, C. & George, W.D. (1998) 'Conservation surgery and specialist treatment'. European Journal of Cancer. 34 (Supplement p. 546).

Kimman, M. Voogd, A. Dirksen, C. Falger ,P. Hupperets, P. Keymeulen, K. Hebly, M. Dehing, C. Lambin, P. & Boersma, L. (2007) 'Improving the quality and efficiency of follow-up after curative treatment for breast cancer – rationale and study design of the MaCare trial' Bio Med. Central (BMC) Cancer 7, (1), p.1

Kiss, A.. & Siegfried, M. (2001) 'Effect of Sex and Gender on Psychological aspect of prostate and breast cancer'. B.M.J. 323, (7320), p.1055-1058.

Kitzinger, J. (1995) 'Introducing focus groups'. B.M.J. 311, (7000), p. 299-302.

Klein, R. (2005) 'A Middle way for rationing healthcare resources'. B.M.J. 330, (7504), p.1340-1341.

Kmietowicz, Z. (2002) 'W.H.O. insists screening can cut breast cancer rates'. B.M.J. 324, (7339), p.695.

Kmietowicz, Z. (2004) 'GPs need help in spotting cancer symptoms report says.' BMJ 328, (7441), p659.

Knobf, M.T. (1998) 'Natural menopause and ovarian toxicity associated with breast cancer therapy'. Oncology Nursing Forum 25, (9), p.1519-1532.

Koch T. (1998) 'Story telling: Is it really research?' Journal of Advanced Nursing 28, (6), p.1182-1190.

Koch, T. (2006) 'Establishing rigour in qualitative research: the decision trail'. The Journal of Advanced Nursing. 53, (1), p.102-103.

Koedoot, C. Oort, F.J. de Hann, R.J. Bakker, P.J.M.D.E. Graeff, A. & Haes, J.C.J.M. (2004) 'The content and amount of information given by medical oncologists when telling patients with advanced cancer what their treatment options are: palliative chemotherapy and watchful waiting'. European Journal of Cancer 40, p.225-235.

Koinberg, I.L. Fridlund, B. & Holmberg, L. (2002) ' Breast cancer patients' satisfaction with a spontaneous system of check-up visits to a specialist nurse'. Scandinavian Journal of Caring Sciences 16, p.209-215.

Koinberg, I.L. Fridlund, B. Engholm, G.B. & Holmberg, L. (2004) 'Nurse led follow-up on demand or by a physician after breast cancer surgery: a randomised study. European Journal of Oncology Nursing 8, (2), p.109-117.

Kolata, G. (1988) 'Breast cancer: anguish, mystery, hope'. New York Times, 24 April, 6:42 (col 1).

Krippendorff, K. (2004) 'Content analysis. An Introduction to its Methodology'. (2nd ed). London: Sage.

Krogstad, U. Hofoss, D. & Hjortdahl, P. (2002) 'Continuity of hospital care: beyond the question of personal contract' B.M.J. 324, (7328), p.36-38.

Krueger R.A. (1988) Focus Groups: a practical guide for applied research. London: Sage.

Krueger, R. A. (1994) Focus Groups: Practical Guide For Applied Research (2<sup>nd</sup> ed.). California: Sage.

Kunkler, I. (1999). 'Perhaps Britain should adopt the French model'. B.M.J. 319, (7224), p.1572.

Lakhani, M. & Baker, M. (2006) 'Good GPs will continue to be essential'. B.M.J. 332, (7532), p.41-42.

Lambert, S. & Loisele, C. (2008) 'Combining interviews and focus groups to enhance data richness'. Journal of Advanced Nursing. 62, (2), p.228-237.

Lampic, C. Thurfjell, E. Berg, J. Carlsson, M. & Sjoden, P. (2003) 'Attainment and importance of life values among patients with primary breast cancer'. Cancer Nursing. 26, (4), p.295 - 304.

Landmark, B. Strandmark, M. & Wahl, A. (2001) 'Living with newly diagnosed breast cancer: the meaning of existential issues'. Cancer Nursing. 24, (3), p.220 –226.

Lane, P. McKenna, H. Ryan, A. & Flemming, P. (2001) 'Focus group methodology" Nurse Researcher 8, (3), p.45-57.

Larson, E., & Yao, X. (2005). 'Clinical empathy as emotional labour in the physician-patient relationship'. The Journal of the American Medical Association 293, (9), p.1100–1106.

Lauver, D. Connolly-Nelson, K. & Vang, P. (2004) 'Stressors and coping strategies among female cancer survivors after treatment'. Cancer Nursing. 30, (2), p.101-111.

Law, R. (2001) 'Political power and empowered clients'. B.M.J. [online]. 323, (7310). Available from <http://www.bmj.com/cgi> [Accessed 24th May 2008]

Lazarus, R.S. & Folkman, S. (1984) 'Stress, appraisal and coping'. New York : Springer.

Lederman, L.C. (1990) 'Assessing educational effectiveness: the focus group interview as a technique for data collection.' Communication Education 38, (2), p.117-127.



Lee, S. Schover, L. Patridge, A. Patrizio, P. Wallace, W.H. Hagerty, Beck, L. Brennan, L. & Oktay, K. (2006) ' American society of clinical oncology recommendations on fertility preservation in cancer patients'. Journal of Clinical Oncology. 24, (18), p. 2917 -2931.

Lees, A. Gabos, A. & Jenkins, H. (1997) 'Investigations for staging and follow-up of breast cancer patients'. Cancer Prevention Control. 1, p.157-160.

Leininger, M.M. (1980) Caring: a central focus of nursing and health care services'. Nursing and Health Care. 1, (3), p.135-143.

Lemp, H. (1995) 'Has nursing lost its way?: No regrets'. B.M.J. 311, (7000), p.307-308.

Lethborg, C.E. Kissane, D. Burns, I. & W. Snyder, R. (2000) 'Cast Adrift – The experience of completed treatments among women with early stage breast cancer'. Journal of Psychosocial Oncology. 18, (4), p.73-90.

Lewis, L. (2006) 'Discussion and Recommendations: addressing barriers in the management of cancer survivors'. American Journal of Nursing 106, (supp 3), p.91-95.

Lewis, M. A. & Rook K.S. (1999) 'Social control in personal relationships: Impact on health behaviours and psychological distress' Health Psychology 18, p.63-71.

Leydon, G. Moynihan, C. Boulton, M. Jones, A. Boudiom, M. & McPherson, K. (2000) 'Cancer patients' information needs and information seeking behaviour: in depth interview study. B.M.J. 320, (7239), p.909-913.

Liedekerken, B.M. Hoogendam, A. Buntinx, F. Van der Weyden, T. & de Vet, H.C. (1997). 'Prolonged cough and lung cancer: the need for more general practice research to inform clinical decision making'. British Journal of General Practice 47, (421), p. 505.

Likert, R. (1932) 'A technique for the measurement of attitudes'. Archives of Psychology. 140, p.256.

Lindley, C. Vasa, S. Sawyer, W. & Winer, E. (1998) 'Quality of life and preferences for treatment following systemic adjuvant therapy for early stage breast cancer' Journal of Clinical Oncology 16, (4), p.1380-1387.

Livestrong [Lance Armstrong Foundation]. [online]. No Date. [www.livestrong.org](http://www.livestrong.org). Accessed 13 July 2008.

Loprinizi, C. Hayes, D. Smith, T. (2000) 'Doc, shouldn't we be getting some tests?' American Society for Clinical Oncology 18, (11), p.2345-2348.

Lovejoy, N.C. Tabor, D. Matteis, M. & Lillis, P. (2000) 'Cancer-related depression: part 1- neurologic alterations and cognitive behavioural therapy'. Oncology Nursing Forum 27, (4), p.667-78; quiz 79-80.

Luce, M.F. (2005) 'Decision making as coping.' Health Psychology 24, (Supplement 4), p.23-28.

Luker, K. Beaver, K. Leinster, S. & Owen, G. (1996) 'The meaning of illness for women with breast cancer.' Journal of Advanced Nursing 23, (6), p.1194-1201.

Lukes, S. (1974) Power: a radical view. London. Macmillan.

Mac Alister, L. & Chiam, M. (1995) 'Why do nurses agree to take on doctors' roles?' British Journal of Nursing 4, (21), p.1238-1239.

Mac Bride, S. & Whyte, F. (1999) 'Attendance at cancer follow-up clinic; does it increase anxiety or provide reassurance for men successfully treated for testicular cancer?' Cancer Nursing 22, (6), p.448 - 455.

Macleod, U. Ross, S. Twelves, C. George, W.D. Gillis, C. & Watt G.M.C. (2000) 'Primary and secondary care management of women with early breast cancer from affluent and deprived areas: retrospective review of hospital and general practice records'. B.M.J. 320, (724), p.1442-1445.

Maguire, P. Tait, A. Brooke, M. Thomas, C. & Sellwood, R. (1981) 'Effects of counselling on the psychiatric morbidity associated with mastectomy' B.M.J 281, p.1454-1456.

Maguire P. (1994) 'Psychological Aspects'. In Dixon J (ed.). ABC of breast diseases. B.M.J. Publishing Group. London.

Maher, J. Bradburn, J. & Adewuyi-Dalton, R. (1995) 'Patients prefer specialist follow-up'. B.M.J. 311, (6996), p.54.

Mairis, E.D. (1994) 'Concept clarification in professional practice: dignity'. Journal of Advanced Nursing. 19, (5), p.947-953.

Mayeroff, M. (1972) 'On Caring'. New York: Harper and Row.

Mayor, S. (2000) 'Emotional exhaustion and stress in doctors are linked'. B.M.J. 324, (7352), p.1475.

Mayor, S. (2001) 'Study confirms that screening reduces deaths from breast cancer.' B.M.J. 322, (7295), p.1140.

Mayor, S. (2003) 'U.K. improves cancer control' B.M.J. 326, (7380), p.72

Mayor, S. (2003a) 'UK specialists predict shortfall in breast cancer services as population ages'. B.M.J. 327, (7406), p72.

Mayor, S. (2006) 'Many cancer networks are failing to improve services' B.M.J. 332, (7535), p.193.

Mayor, S. (2009) 'Report shows wide variation in cancer survival across England'. B.M.J. [online] 339(b5207), Available from:  
<http://www.bmj.com/cgi/content/extract/339/dec> [Accessed 8th December 2009]

Mays, N. & Pope, C. (1995), 'Qualitative research: rigor and qualitative research.' B.M.J. 311, (6997), p.109 -112.

McCaughan, E. & Sorley, O. (2007) 'Consumers' and professionals' perceptions of a breast clinic review clinic'. Journal of Advanced Nursing 60, (4), p.419 - 426.

McCoy, J. (2004) 'Chemotherapy as a treatment for breast cancer' in V. Harmer (ed). Breast cancer nursing care and management. London : Wiley p.150 -169.

McGhee, G. Marland, G, & Atkinson, J. (2007) 'Grounded theory research: literature reviewing and reflexivity.' *Journal of Advanced Nursing* [online]. 60, (3), Available from <http://www3.interscience.wiley.com> [Accessed date 22<sup>nd</sup> June 2009].

McIntosh, S.A. Ogston, K.N. Payne, S. Miller, I, Sarkar, T. Hucheen, A. & Heys, S. (2003) 'Local recurrence in patients with large and locally advanced breast cancer treated with primary chemotherapy' American Journal of Surgery 185, (6), p.525-531.

McKinley, E.D. (2000) 'On being a patient. Under toad days: Surviving the uncertainty of cancer recurrence'. Annals of International Medicine 133, (6), p.479-480.

McPherson, K. Steel, C.M. & Dixon, J.M. (2000) 'Breast Cancer epidemiology, risk factors and genetics' B.M.J. 321, (7261), p. 624-628.

McQueen, D. (2002) 'Discomfort of patient power'. B.M.J. 324, (7347), p.1214.

McSharry, M. (1995) 'The evolving role of the clinical nurse specialist'. British Journal of Nursing 4, (11), p.641-646.

Mead N, Varnam R, Rogers A, & Poland M. (2003)' What predicts primary care patients' interest in the internet as a health resource? A questionnaire study'. Journal of Health Service Research and Policy 8, (1), p.33-39.

Meric, F. Bernstam, E. Mirza, N. Hunk, K. Ames, F. Ross, M. Kuerer, H. Pollock, R. Museum, M. & Singletary, S. (2002) 'Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. B.M.J. 324, (7337), p.577-581.

Meridith, C. Symonds, P. Webster, L. Lamont, D. Pyper, E. Gillis, C.R. & Fallowfield, L. (1996) 'Information needs of cancer patients in West Scotland: cross sectional survey of patients views'. B.M.J. 313, (7059), p.724-726.

Meyer, T. J. & Mark, M.M. (1995) 'Effects of psychological interventions with adult cancer patient: a meta-analysis of randomised experiments' Health Psychology 14, (2), p.101-108.

Middleton, J. McKinley, R. & Gillies, C. (2006) 'Effect of patient completed agenda forms and doctors' education about the agenda on the outcome of consultations: randomised controlled trial'. B.M.J. 332, (7552), p.1238-1242.

Millar, B. Maggs, C. Warner, V. Whale, Z. (1996) 'Creating consensus about nursing outcomes. I. An exploration of focus group methodology'. Journal of Clinical Nursing. 5, (3), p.193-197.

Mishel, M.H. (1988) 'Uncertainty in illness'. Image Journal of Nursing Scholarship 20,(4) p.225-232.

Mishel, M.H. & Braden, C.J. (1988) 'Finding meaning; antecedents of uncertainty in illness'. Nursing Research 37, (2), p.98-103.

Miyashita, M. (2005) 'A randomised intervention study for breast cancer survivors in Japan: effects of short term support group focused on possible breast cancer recurrence'. Cancer Nursing 28, (1), p.70-78.

Mohoney, L. (1986) 'Methods for detecting locally recurrent and contralateral second primary breast cancer'. Canadian Journal of Surgery. 29, (5), p.372-373.

Mongelli, M. (2002) 'Nurse led care for cancer patients: beware of bias'. B.M.J.[online]. 375, (7373) Available from [www.bmj.com/cgi/eletters/325/7373/1145](http://www.bmj.com/cgi/eletters/325/7373/1145) [Accessed 22 June 2008].

Montazeri, A. Jarvandi, S. Haghighats, S. Vahdani, M. Sajadian, A. Ebrahimi, M. & Haji - Mahmoodi, M. (2001) 'Anxiety and depression in breast cancer patients before and after participation in cancer support group'. Patient Education and Counselling. 45, (3), p.195-198.

Montgomery, D. A. Krupa, K. Jack, W. Kerr, G. Kunkler, I. Thomas, J. & Dixon, J. M. (2007) 'Changing pattern of recurrence detection in breast cancer: The Edinburgh Experience'. British Journal of Cancer 96, (12),p.1802-1807

Montgomery, D. A. Krupa, K. Cooke, T. G. (2007a)' Alternative methods of follow-up in breast cancer: a systematic review of the literature'. British Journal of Cancer. 96, (11), p.1625-1632.

Montgomery D., A., Krupa K., Cooke T.,G., (2007b) 'Follow-up in breast cancer: does routine clinical examination improve outcome? A systematic review of the literature'.

British Journal of Cancer. [online]. 97, (12), p.1632-1641. Available from [www.bjcancer.com](http://www.bjcancer.com) [Accessed 22 June 2008].

Moore, K. Estey, A. (1999) 'The early post-operative concerns of men after radical prostatectomy'. Journal of Advanced Nursing. 29,(5),p.1121-1129.

Morgan, D. (1993) Successful Focus Groups London: Sage

Morgan, D.L. and Krueger, R.A. (1993) 'When to use focus groups and why. In D.L. Morgan (ed.) Successful focus groups: Advancing the state of the Art. Sage Publications London, p.3-19.

Morrall, P. (2001) 'The spectre of realism' Australian & New Zealand Journal of Mental Health Nursing 10, (2), p.128-130.

Morrow, S. Haverkamp, B. & Ponterotto, J. (2005) 'A Time and Place for Qualitative and Mixed Methods in Counselling Psychology Research'. Journal of Counselling Psychology. Special Issue: Knowledge in Context: Qualitative Methods in Counselling Psychology Research. 52, (2), p.123-125.

Morse, J. & Field, P. (1996) Nursing Research. The Application of Qualitative Approaches. (2<sup>nd</sup> ed). Chapman & Hall. London.

Morse, J. (2000) 'Researching Illness and Injury: Methodological Considerations'. Qualitative Health Research 10, (4) p.538-546.



Morse, J. (2002) 'Qualitative Health Research; Challenges for the 21<sup>st</sup> Century'. Qualitative Health Research. 12, (1), p.116-129.

Mulholland, J. (1997) 'Assimilating sociology: critical reflections on the sociology in nursing debate'. Journal of Advanced Nursing 25 (4) p.844-852.

Muss, H.D. Case. L.D. Tell, G.S. & Atwell, B.M. (1991) 'The perceptions of follow-up care in women with breast cancer.' American Journal of Clinical Oncology. 14, (1), p.55-59.

Murata, H. (2003) 'Spiritual pain and its care in patients with terminal cancer: construction and conceptual framework by philosophical approach'. Palliative Supportive Care 1, (1), p.15-21.

Mutrie, N. Campbell, A.M. Whyte, F. McConnachie, A. Emslie, C. Lee, L. Kearney, N. Walker, A. & Ritchie, D. (2007) 'Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial' B.M.J. 334, (7592), p.517.

Nay, R. (1998) 'Contradictions between perceptions and practices of caring in long-term care of elderly people'. Journal of Clinical Nursing. 7, (5), p.401- 408.

National Comprehensive Cancer Network (2003) 'Distress management clinical practice guidelines in oncology.' Journal of National Comprehensive Cancer Network 1, (3), p.344-374.

N.H.S.B.S.P. [Homepage of National Health Service Breast Screening Programme]. [Online]. No date for update. Available from <http://www.nmc-uk.org> [Accessed 6 June 2008].

N.H.S. Management Executive (1992) 'Local Voices; the views of local people in purchasing for health' DOH. London.

Nestral, D. (2001) 'Power and patient-centred care'. B.M.J. [online]. 323 (7310). Available from <http://www.bmj.com/cgi>

NICE (National Institute for Clinical Excellence). 'Follow-up after treatment for early breast cancer. In guidance on cancer services. improving outcomes in breast cancer. manual update'. London, UK: National Institute for Clinical Excellence 2002; p.58–64.  
[www.nice.org.uk/page.aspx?o=csgbcbguidance](http://www.nice.org.uk/page.aspx?o=csgbcbguidance)

NICE (2004) 'Supportive and palliative care for people with cancer'. NICE. London.  
[www.nice.org.uk](http://www.nice.org.uk)

Njor, A.H. Vejborg, S. W. Schwartz, W'. Dalgaard, P. Jensen, M.B. Tange, U.B. Blichert-Toft, M. Rank, F. Mouridsen, H. & Lynge, E. (2005) Breast cancer mortality in Copenhagen after introduction of mammography screening: cohort study'. BMJ 330, (7485) p.220-222.

Nordgen, S. & Fridlund, B. (2001) 'Patient's perceptions of self determination as expressed in the context of care'. Journal of Advanced Nursing. 35, (1), p.117-129.

Nursing and Midwifery Council (2004) 'The Nursing and Midwifery Council code of conduct: Standards for Conduct, performance and ethics.' [Online] August 2008. [www.nmc-uk.org](http://www.nmc-uk.org) [Accessed 22 August 2008].

Nursing and Midwifery Council (2004a) Standards of proficiency for preregistration Nursing Education. London, NMC.

Nursing and Midwifery Council (2004b) Fitness to practice annual report 2002-2003. London NMC.

Nyamathi, A. & Shuler, P. (1990) 'Focus Group Interview: a research technique for informed nursing practice.' Journal of Advanced Nursing. 15, p1281-1288.

Nyström, L. Rutqvist, L.E. Wall, S. Lindgren, A. Andersson, I. Lindqvist, M. Ryden, S. Bjurstam, N.Fagerberg, G. & Frisell, J. (1993) 'Breast cancer screening with mammography: overview of Swedish randomised trials'. The Lancet 341, (8851), p.973-978.

O'Dowd, A. (2007) 'Cancer survival in UK is improving but could be better'. B.M.J. 335, (7616), p. 363.

O'Hagan, B. Carroll, D. & Dodds, J. (2005) 'Patients accelerating change' Nursing Management 12, (2), p.18-21.

Office for National Statistics. Cancer Statistics – Registrations, England and Wales. (1993) Series MBI No 26 London : HMSO1999.

Office for National Statistics, Cancer Statistics registrations: Registrations of cancer diagnosed in 2004, England. Series MB1 no.35. 2007, National Statistics: London.

Office for National Statistics [Homepage of Office for National Statistics]. [Online]. No Date. Available from : <http://www.statistics.gov.uk> [Accessed 18 July 2008].

Office of Public Sector Information (1998) Human Rights Act Chapter 42. Available from [www.opsi.gov.uk/ACTS/acts 1998](http://www.opsi.gov.uk/ACTS/acts 1998).

Okamura, M. Yamawaki, S. Akechi, T. Taniguchi, K. & Uchitomi, Y. (2005) 'Psychiatric disorders following first breast cancer recurrence: prevalence, associated factors and relationship to quality of life'. Japanese Journal of Clinical Oncology. [online] 35 (6) Available from : <http://jjco.oxfordjournals.org/cgi/content/abstract/35/6/302> [Accessed 25th April 2009).

Olsen, A. Njor, S.Vejborg, I. Schwartz, W. Dalgaard, P. Jensen, M. Tange, U. Blichert-Toft, M. Rank, F. Mouridsen, M. & Lynge, E. (2005) 'Breast Cancer mortality in Copenhagen after the introduction of mammography screening: cohort study'. B.M.J. 330, (7485), p.220.

Olivier, M. (1996a) Understanding disability: from theory to practice Basingstoke: Macmillan.

Ong, B.N. (1993) The Practice of Health Service Research. London: Chapman & Hall.

Orb, A. Eisenhauer, L. & Wynaden, D. (2001) 'Ethics in qualitative research'. Journal of Nursing Scholarship 33, (1), p.93-96.

Orem D.E. (1991) Nursing: Concepts of Practice (4<sup>th</sup> ed). St Louis, Mosby Year Book.

Orne, M. (1968) 'On the nature of effective hope' International Journal of Psychiatry.5, (5), p.403-410.

Paniagua, H. (1997) 'Are nurse practitioners a viable option?' British Journal of Nursing 6, (5), p.245.

Papagrigoriades, S. & Heyman, B. (2003) 'Patients views on follow-up of colorectal cancer: implications for risk communication and decision making'. Post Graduate Medical Journal. 79, (933), p.403-407.

Papenhausen, J.L. & Beecroft, P.C. (1990) Specialization vis-à-vis the clinical nurse specialist'. Clinical Nurse Specialist 4, (2), p.61–62.

Parahoo, K. (1997) Nursing research: principles, process and issues. London. Macmillan.

Parahoo, K. (2006) Nursing Research. Principles, Process and Issue (2<sup>nd</sup> ed) London Macmillan.

Parsons, T. (1951) The Social System London: Routledge and Kegan Paul.

Partridge, A.H. & Winer, E.P. (2004) 'Long term complications of adjuvant chemotherapy for early stage breast cancer'. Breast Disease 24, p.55-64

Pascoe, S.W. Neal, R.D. Allgar, V.L. Selby, P.J. & Wright, E.P. (2004) 'Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care'. Family Practice 21, (4), p. 437– 442.

Passik, S. McDonald, M. Rosenfeld, B. Theobald, D. & Edgerton, S. (1998) 'Oncologists' recognition of depression in their patients with cancer'. Journal of Clinical Oncology. 16, (4), p.1594-6000.

Patton, M.Q. (2002) Qualitative Research and Evaluation Methods. (2<sup>nd</sup> ed). London: Sage.

Peabody, F. (1927) 'The care of the patient'. Journal of American Medical Association. 88, p.876-882.

Peck, S.A. (2000) 'Nurse practitioner response'. B.M.J. [online] 320, (7241), available from [www.bmj.com/cgi/eletters/320/7241/1804#7422](http://www.bmj.com/cgi/eletters/320/7241/1804#7422) Accessed 15th June 2008.

Pellegrino, E. (1990) 'The relationship of autonomy and integrity in medical ethics'. Bulletin of Pan American Health Organisation 24, (4), p.361-371.

Pelusi, J. (2006) 'Sexuality and body image: research on breast cancer survivors documents altered body image and sexuality' American Journal of Nursing. 106, (Supplement 3), p.32-38.

Pennery, E. & Mallet, J. (2000) 'A preliminary study of patients perceptions of routine follow-up after treatment for breast cancer.' European Journal of Oncology Nursing. 4, (3), p.138-145.

Pestalozzi, B. (2007) 'Primary breast cancer: European Society for Medical Oncology Clinical Recommendations for diagnosis, treatment and follow-up'. Annals of Oncology 18, (Supplement 2), p.ii5.

Peto, R. Boreham, J. Clarke, M. Davies, C. & Beral, V. (2000) 'UK and USA breast cancer deaths down 25% in year 2000 at ages 20-69 years'. The Lancet 355, (9217). p.1822.

Pickersgill, T. (2001) 'The European working time directive for doctors training'. B.M.J. 323, (7324), p.1266.

Pierce, J. Stefanick, M. Natarajan, L. Sternfeld, B. Madlensky, L. Al-Delaimy, W. Thomson, C. Kealey, S. Hajek, R. Parker, B. Newin, V. Caan, S. & Rock, C.(2007) 'Greater survival after breast cancer in physically active women with high vegetable-fruit intake regardless of obesity.' Journal of Clinical Oncology. 25, (17), p.2345-2351.

Pine, M. ([Mike.pine@bcf.nhs.uk](mailto:Mike.pine@bcf.nhs.uk)). (30th November 2006). Message from Professor Mike Richards on the future of cancer services. Email to L. Kelly ([Lorraine.Kelly@bcf.nhs.uk](mailto:Lorraine.Kelly@bcf.nhs.uk)).

Polit, D. & Beck, C. (2004) Nursing Research Principles and Methods. (7<sup>th</sup> ed). Philadelphia: Lippincott.

Polit, D. & Hungler, B. (1998) Nursing Research: Principles and Methods (6<sup>th</sup> ed) London J.P.Lippincott.

Pollock, K. Grime, J. & Mechanic, D. (2002) Patients' perceptions of entitlement to time in general practice consultations for depression: qualitative study' B.M.J. 325, (7366), p.687.

Popay, J. & Williams, G. (1994) Researching the people's health. London Routledge. p.46-57.

Porrett T., (1996) 'Extending the role of the stoma care nurse' Nursing Standard 10, (27), p.33-35.

Primeau, L.A. (2003) 'Reflections on self in qualitative research stories of family'. American Journal of Occupational Therapy. 571 p9-16.

Punch, K. (1998) Introduction to Social Research Sage London.

Quinn, M. & Allen, E. (1995) 'Changes in incidence and mortality from breast cancer in England and Wales since the introduction of screening'. B.M.J. 311, (7017), p.1391-1395.

Rainsbury, D. (1996) 'Routine follow-up of breast cancer in primary care'.B.M.J. 313, (7071) p.1547.

Raphael, D. & Bryant, T. (2002) 'The limitations of population health as a model for a new public health'. Health Promotion International 17 (2) p189-199.

Rawls, J. (1972) A theory of Justice. Oxford: University Press.



Read, S. Lloyd-Jones, M. Collins, K. McDonnell, A. Jones, R. Doyal, L. Cameron, A. Masterson, A. Dowling, S. Vaughan, B. Furlong, S. & Scholes J. (1999) Exploring new roles in practice. University of Sheffield. SCHARR. [Online] Available from <http://www.shef.ac.uk/content/1/c6/01/33/98/enrip.pdf> [Accessed 19.8.2008].

Reed, J. & Parton, V. (1997) Focus groups: issues of analysis and interpretation Journal of Advanced Nursing 26, (4), p. 765-771.

Reed, J. & Proctor, S. (1995) 'Practitioner research in context' In Reed, J. & Proctor, S (eds) Practitioner research in health care : the inside story. London: Chapman and Hall, p.3-31.

Reed, J. Weiner, R. & Cook, G. (2004) 'Partnership research with older people- moving towards making the rhetoric a reality'. International Journal of Older People in Nursing. 13 (3a) p.3-10.

Reeves, P. (2001) 'How individuals coping with HIV/AIDS use the internet'. Health Education Research 16, (6), p.709 -719.

Reid, I. (1998) 'Patients' preference for male or female breast surgeons: questionnaire study' B.M.J. 317, (7165), p.1051-1060.

Renehan, A.G. O'Dwyer, S. & Whynes, D.K. (2004) 'Cost effectiveness analysis of intense follow-up after curative resection for colorectal cancer'. B.M.J. 328, (7431), p.81.

Renton, J.P. Twelves, C.J. & Yuille, F.A.P. (2002) 'Follow-up in women with breast cancer : the patients' perception' The Breast 11, (3), p.257-261.

Revenson, T. & Pranikoff, J. (2005) 'A contextual approach to treatment decision making among breast cancer survivors' Health Psychology. 24, (4), Supplement p S93- S98.

Richards, T. (1998) 'Partnership with patients'. B.M.J. 316, (7125), p.85-86.

Richards, M.A. Westcombe, A.M. Love, S.B. Littlejohns, P. & Ramirez, A.J. (1999) 'Influence of delay on survival in-patients with breast cancer: a systematic review. The Lancet. 353, (9159), p.1119-11126.

Richards, M.A. Wolfe, O.D.A. Tilling, K. Barton, J. Bourke, H.M. Gregory, W.M. (1996) 'Variations in management and survival of women under fifty years with breast cancer in the South Thames Region'. British Journal of Cancer. 19, p.751-757.

Roberts, P. Priest, H. & Traynor, M. (2006) 'Reliability and validity in research' Nursing Standard 20, (44), p.41-45.

Robinson D. Bell J. & Möller H (2000) 'Comparing survival rates between different registries can be difficult'. BMJ. 321, (7270), p.1227a

Robson, C, (1993) 'Real World Enquiry', C Robson (ed) Real World Research Oxford Blackwell.

Robson, P. Locke, M. & Dawson, J. (1997) Consumerism or democracy? User involvement in the control of voluntary organisations. Bristol: The Policy Press.

Robson, C. (2002) 'Real World Research: A Resource for Social Scientist and Practitioner-Researchers'. (2<sup>nd</sup> edn) London: Blackwell.

Rodger, A. (2002) 'Is it a trial of nurse led follow-up or of plenty time?' B.M.J. [online]. 325, (7373), Available from  
<http://www.bmj.com/cgi/eletters/325/7373/1145#27855> [Accessed 23<sup>rd</sup> July 2008]

Roland, M. (2002) 'Contract needs to enable doctors to offer first class care'. B.M.J. [online]. 325, (7374). Available from: <http://www.bmj.com/325/7374/1241> Accessed 10<sup>th</sup> May 2008.

Rolls, L. & Relfe, M. (2004) 'Bracketing Interviews': a method for increasing objectivity in bereavement and palliative care.' Mortality. [online] 11,(3),p.286 - 305. Available from:  
<http://www.ingentaconnect.com> [Accessed 23<sup>rd</sup> July 2008].

Rosenzweig, M. (2006) 'The oncology nurse practitioner: a unique provider for the follow-up for early-stage breast cancer'. Journal of Clinical Oncology. 4, (22), p.3710-3711; author reply 3711-3712.

Ross, F. Donovan, S. Brearley, S. Victor, C. Cottee, M. Crowther, P. & Clarke, E. (2005) 'Involving older people in research: methodological issues'. Health and Social Care in the Community. 13 (3), p.268-275.

Rosselli Del Turco, M. Palli, D. Cariddi, A. Ciatto, S. Pacini, P. Distanto, V. (1994). 'Intensive diagnostic follow-up after treatment of primary breast cancer: a randomised trial'. Journal of the American Medical Association. 271, (20), p.1593-1597

Rustøen, T. & Begnum, S. (2000) "Quality of life in women with breast cancer. A review of the literature and implications for nursing practice. Cancer Nurse 23, (6), p.416-421.

Rutgers, E.J.T. van Rossum, A.B. Peterse, J.L. Cohen, P. Borger, J.H. & Kemperman H.W. (1991) 'Breast conserving surgery for invasive carcinoma: diagnosis of local recurrence'. Netherlands Journal of Surgery. 43, (4), p.110-113.

Saarni, S. & Gylling, H. (2004) 'Evidence based medicine: A solution to rationing or politics disguised as science?' Journal of Medical Ethics. 30, (2), p.171-175.

Sainio, C. & Lauri, S. (2003) 'Cancer patients' decision-making regarding treatment and nursing care' Journal of Advanced Nursing. 41, (3), p.250-260.

Salander, P. (2002) 'Bad news from the patient's perspective: An analysis of the written narrative of newly diagnosed cancer patients' Social Science & Medicine 55, (5), p.721-732.

Sammarco, A. (2001) 'Perceived Social Support Uncertainty, and Quality of Life of younger breast cancer survivors'. Cancer Nursing. 24, (3), p.212-219.

Sant, M. Capocaccia, R. Verdecchia, A. Esteve, J. Gatta, G. Micheli, A. Coleman, M.P. & Berrino, F. (1998) 'Survival of women with breast cancer in Europe: variation with age, year of diagnosis and country'. International Journal of Cancer. 77, (5), p.679-683.

Sant, M. Berrino, F. & Coeberg, J.W.W. (1999). 'Reliable data on stage distribution are essential'. B.M.J. 319, (7224), p.1572.

Sardell, S. Sharpe, G, Ashley, S. Guerrero, D. & Brada, M. (2000) 'Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma'. Clinical Oncology. (Royal College of Radiology. Great Britain) 12 (1) p.36-41.

Schapira, D.V. & Urban, N. A. (1991) 'A minimalist policy for breast cancer surveillance. Journal of American Medical Association. 16, 265, (3) p.380-382.

Schultz, P.N. Klein, M.J. Beck, M.L. Stava, C. & Sellin, R.V. (2005) 'Breast cancer: relationship between menopausal symptoms, physiologic health effects of cancer treatment and physical constraints on quality of life in long term survivors. Journal of Clinical Nursing 14, (9), p.204-211.

Schroeder, C. & Neil, R. (1992) 'Focus groups: a humanistic means of evaluating an hiv/aids programme based on caring theory'. Journal of Clinical Nursing. 1,(5), p.265-274.

Schnipper, H. (2001) 'The art of oncology: when the tumour is not the target - life after breast cancer.' Journal of Clinical Oncology 19 (15) p.3581-3584.

Seedhouse, D. (1986) 'Health: The foundations for achievement'. John Wiley: London.

Sharp, K. (1998) 'The Case for case studies in nursing research: the problem of generalisation'. Journal of Advanced Nursing. 27, (4), p.785-789.

Sharp, J.W. (1999) 'The Internet: Changing the way cancer survivors obtain information'. Cancer Practice. 7, (5), p.266-269.

Shepherd J (1993) 'Nurses are changing not extending their roles'. British Journal of Nursing. 2, (9), p.447.

Sikora, K. (1999) 'Cancer survival in Britain' B.M.J. 319, (7208), p. 461-462.

Silverman, D. (2000) Doing Qualitative Research A Practical Handbook. London, Sage.

Sim, J. & Sharp, K. (1998) 'A critical appraisal of the role of triangulation in nursing research.' International Journal of Nursing Studies. 35, (1), p.23-31.

Siminoff, L.A. Ravdin, P. Colabianchi, N. & Sturm, C.M. (2000) 'Doctor - Patient communication patterns in breast cancer adjuvant therapy decisions'. Health Expectations. 3, (1) p26-36.

Siminoff, L.A. & Step, M.M. (2005) 'A communication model of shared decision making: Accounting for cancer treatment decisions'. Health Psychology 24, (Suppl.4), S99-S105.

Simon, C.E. Crowther, M. & Higgerson, H. (2007) 'The stage-Specific role of Spirituality among African American Christian women throughout the breast cancer experience'. Cultural Diversity and Ethnic Minority Psychology 13, (1), p.26-34.

Singleton, J. & McLaren, S. (1995) 'Ethical Foundation of Health Care: Responsibilities in Decision Making'. London: Mosby.

Skilbeck, J. Payne, S. (2003) 'Emotional support and the role of the clinical nurse specialists in palliative care' Journal of Advanced Nursing 43, (5). P. 521 - 530

Sloan, G. (1998) 'Focus Group interviews: defining clinical supervision'. Nursing Standard 12, (42), p.40-43.

Slovic, P. Peters, E. Finucane, M.F. & MacGregor, D.G. (2005) 'Affect, risk and decision making'. Health Psychology 24, (Suppl4), S.35- S40.

Small, N. & Rhodes, P. (2000) 'Too ill to talk? User Involvement in palliative care'. London: Routledge.

Smeeth, L. & Fletcher, E. (2002) 'Improving the Response Rates to Questionnaires' B.M.J. 3324, (7347), p1168-1169.

Smith, G. (1980) Social Need London: Routledge Kegan & Paul.

Smith, T.J. Davidson, N.E. Schappira, D.V, Grunfeld, E. Muss, H.B. Vogel, V. G. & Somerfields, M.R. (1999) 'American sociology and clinical oncology 1998 update of recommended breast cancer surveillance guidelines'. Journal of Clinical Oncology 17, (3), p.1080 -1082.

Smythe, M. McCaughan, E. & Harrison, S. (1995) 'Women's perceptions of their experiences with breast cancer are their needs being addressed?' European Journal of Cancer Care 4, (2),p.86-92.

Snee, M. (1996) 'Follow-Up of women treated for breast cancer'. Clinical Oncology 8, p.85-89.

Sparbel, K.J. & Anderson, M.A. (2000) 'Integrated literature review of continuity of care. Part 1: conceptual issues'. Journal of Nursing Scholarship. 32, (1), p.17-24.

Spear, N. (2006) 'In response to: Koch T. (2006) 'Establishing rigour in qualitative research: the decision trial'. Journal of Advanced Nursing. 53, (1), p.91-100.

Speigel, D. Bloom, J.R. & Yalom, I. (1981) 'Group support for patients with metastatic cancer: a randomised prospective outcome study' Archives of General Psychiatry. 38, (5), p.527-533

Spence, R.A.J. & Johnson, P.G. (2001) Oncology Oxford University Press.

Spurgeon, D. (2001) Breast self examination may do more harm than good' B.M.J. 323, (7303), p.11.

Stanton, A. (2006) 'Psychosocial concerns and interventions for cancer survivors.' Journal of Clinical Oncology 24, (32), p.5132-5137.

Stead, M. Fallowfield, L. Brown, J. & Selby, P. (2001) 'Communication about sexual problems and sexual concerns in ovarian cancer: qualitative study' B.M.J. 323, (7317), p836-837.

Steer,C. & Lee,C. (2004) "Art of oncology: when the tumour is not the target". Journal of Clinical Oncology, 22, (23), p. 4804-4806.



Stewart, D. & Shamdasani, P. (1990) Focus Groups: Theory and Practice Newbury Park, Sage.

Summerton, N. (1999). 'Diagnosis in primary care is an important factor'. B.M.J. 319, (7224), p.1572.

Suominen, T. Leino-Kilpi, H. & Laippala, P. (1994) 'Nurses' role in informing breast cancer patients" and nurses opinions'. Journal of Advanced Nursing 19, (1), p.6-11.

Symthe, M. McCaughan, & E. Harrison, S. (1995) 'Women's perceptions of their experiences with breast cancer: are their needs being addressed' European Journal of Cancer Care. 4, (2), p.86-92.

Tate, J.T. Clifford, P.C. Royle, G.T. & Buchanan, R.B. (1989) 'After surgery for breast cancer: which mode of surveillance? Journal of the Royal Society of Medicine. 82, (12), p.737-738.

Taylor, E. Ismail, S. Hills, H. & Ainsworth, S. (2004) 'Multicomponent psychosocial support for newly diagnosed cancer patients: participants' views' International Journal of Palliative Nursing 10, (6), p.287-295.

Taylor, P. (2005) 'Making decisions about mammography'. B.M.J. 330, (7497), p.915-916.

Teasdale, C. (2001) 'Power and concordance.' B.M.J. [online]. 323, (7310). Available from <http://www.bmj.com/cgi> [Accessed 17th March 2008].

Temple, L.K. Wang, E.E. McLeod, R.S. (1999). 'Preventive health care 1999 Update: 3. Follow-up after breast cancer'. Canadian Medical Association Journal 161, (8), p.1001-1008.

The Bristol Royal Infirmary Inquiry (2001). [Online]. Available from <http://www.bristol-inquiry.org.uk/index.htm> [Accessed 14<sup>th</sup> August 2008].

The Royal Liverpool Children's Inquiry. Summary and Recommendations (2001) House of Commons. [Online]. Available from <http://www.rlcinquiry.org.uk/download/sum.pdf> Accessed 14th August 2008].

The Shipman Inquiry -The Final Report (2005) [Online] Available from <http://www.the-shipman-inquiry.org.uk/home.asp> [Accessed August 14th 2008].

Thewes, B. Butow, P. & Pendlebury, S. (2004) 'Psychosocial needs of breast cancer survivors: a qualitative study of shared and unique needs of younger versus older survivors'. Psycho -Oncology 13, (3), p.177-189.

Thompson, H. Little, M. Jacob, S. & Coker, C. (2006) 'Post treatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: an exploratory qualitative study' Cancer Nursing 29, (6), p.478-487.

Tierney, W. & McKinley, E. (2002) 'When the physician – researcher gets cancer: Understanding cancer, it's treatment and quality of life from the patient's perspective. Medical Care 40, (6 Supplement), III 20 – III 27.

Till, J. & McMulloch, E. (1961) 'A direct measurement of radiation sensitivity of normal mouse bone marrow cells' Radiation Research 14, (2), p.1419-1430.

Tomiak, E. & Piccart, M. (1993) 'Routine follow-up of patients after primary therapy for early breast cancer: changing concepts and challenges for the future'. Annals of Oncology. 4, (3), p.199-204.

Tomin, R. & Donegan, W.L. (1987) 'Screening for recurrent breast cancer-its effectiveness and prognostic value'. Journal of Clinical Oncology. 5, p.62-67.

Tritter, J.Q. Barley, V. Daykin, N. Evans, S. McNeil, J Rimmer, J. Sanidas, M. & Turton, P. (2003) 'Divided care and the third way: user involvement in statutory and voluntary sector cancer services' Sociology of Health and Illness 25, (5), p. 429-456.

Trivedi, P. & Wykes, T. (2002) 'From passive subjects to equal partners –qualitative review of user involvement in research'. British Journal of Psychiatry. 181 p.468-472.

Tuckett, A. (2004) 'Qualitative research sampling: the very real complexities.' Nurse Researcher 12, (1), p.47-61.

Tuckett, A. (2005) 'Part II. Rigour in qualitative research: complexities and solutions'. Nurse Researcher. 13, (1), p.29-42.

Turner, M. (2004) 'Psychological issues for the patient with breast cancer. In: V. Harmer, Editor, Breast Cancer, Nursing Care and Management' London: Wiley, p. 312–334.

Ungerson, C. (1987) 'Policy and personal' London: Tavistock.

Ungoed-Thomas, A. (1997) 'Principles of autonomy' ethics in professional practice'. Middlesex University. Unpublished.

UK Statistics Authority [Home page of UK Statistics Authority]. [Online]. 4 July 2008. Available from [www.statistics.gov.uk](http://www.statistics.gov.uk) [Accessed 6 July 2008].

Vachon, M. (2006) 'Psychosocial distress and coping after cancer treatment: How clinicians can assess distress and which interventions are appropriate – what we know and what we don't.' American Journal of Nursing. 106 (3 ) p.26-31.

Van der Sangen, J.W.W. van de Poll-Franse, L.V. Roumen, R.M.H. Rutten, H.J.T. Coebergh, J.W.W. Vreugdenhil, G. & Voogd, A.C. (2006) 'The Prognosis of patients with local recurrence more than five years after breast conservation therapy for invasive breast carcinoma'. European Journal of Surgery 32, (1), p.34-38.

Vaughan, S. Schumm, J. & Sinagub, J. (1996) Focus group interviews in education and psychology. London: Sage Publication.

Vellone, E. Rega, M. Galletti, C. & Cohen, M. (2006) 'Hope related variables in Italian cancer patients'. Cancer Nursing. 29, (5), p.356-366.

Vickberg, S.M.J. (2003) 'The concerns about recurrence scale (CARS): A systematic measure of women's fears about the possibility of breast cancer recurrence'. Annals of Behavioural Medicine 25, p.16-24.

Viva, C. Canga, N. Canga, A.D. & Arantzamendi, M. (2009) 'The psychosocial impact of recurrence on cancer survivors and family members: a narrative review'. Journal of Advanced Nursing. 65, (4), p. 724-736.

Walker, L.G. & Emerin, O. (1995) 'Neuroimmunology: a new fad or the fifth cancer treatment modality' American Journal of Surgery 170, p. 2-4.

Watts, G. (2003) 'Restoring the profession's self – esteem'. B.M.J. 326, (7382), p.183.

Webb, C. (1996) 'Action research' In Cormack, D. (ed) The Research Process in Nursing. Oxford: Blackwell Science.

Webb, C. & Kevern, J. (2001) 'Focus groups as a research method: a critique of some aspects of their use in nursing research'. Journal of Advanced Nursing 33, (6), p. 798-805.

Weinberg, R. (1996) 'How cancer arises'. Scientific American September Review Issue what you need to know about cancer p.32-40.

Weiner, L.S. Dupont-Spence, E. Davidson, R. & Fair, C. (1993) 'National telephone support groups: a new avenue toward psychosocial support for hiv – infected children and their families'. Social Work with Groups 16, (3), p.55-71.

Weinert, C. Cudney, S. & Winters, C. (2005) 'Social support in cyberspace: the next generation' Computers Informatics Nursing 23,(1), p. 7-15.

Wertheimer, M.D. (1991) 'Against minimalism in breast cancer follow-up'. Journal of American Medical Association. 265, (3), p.396-397.

Wheeler, J.R.C. (2003) 'Can a disease self management program reduce health care costs? The case of older women with heart disease'. Medical Care 41, (6), p.706-715.

White, C. A. & Macleod, U. (2002) 'Clinical review ABC of psychological medicine – cancer' B.M.J. 325, (7360), p. 377-380.

Wickerham, L. Fisher, B. & Cronin, W. (1984) 'The efficacy of bone scanning in the follow-up of patients with operable breast cancer'. Breast Cancer Research and Treatment 4, (4), p.303-307.

Wilding, P. (1982) 'Professional power and social welfare'. London Routeledge & Kegan Paul.

Willard, C. & Luker, K. (2005) 'Supportive care in the cancer setting: rhetoric or reality?' Palliative Medicine 19, (4), p.328-333.

Williams, B. (1994) 'Patient satisfaction: a valid concept?' Social Science Medicine 38, (4), p.509-516.

Williams, S. (2005) 'Parson's revisited: from the sick role to...?' Health 9, (2), p.123-144.

Williamson, G. (2005) 'Illustrating triangulation in mixed methods nursing research'. Nurse Researcher 12, 4 p.7-18.

Wilmot, S. (2003) 'Ethics, power and policy; the future of nursing in the NHS'. Basingstoke, Palgrave.

Wilmoth, M.C. (2001) 'The aftermath of breast cancer: an altered sexual self. Cancer Nursing 24, (4), p.278-86.

Wilson, T. & Sheikh, A. (2002) 'Enhancing public safety in primary care'. B.M.J. 324, (7337), p.584-587.

Wolf, M. H. Putnam, S. M. James, S. & A. Stiles, W. B. (1978)' The medical interview satisfaction scale' Journal of Behavioural Medicine 1, (4) p.391-401.

Wolinsky, F. & Wolinsky, S.R. (1981) 'Expecting sick role legitimisation and getting it' Journal of Health and Social Behaviour. 22, (3), p.229-242.

Wonghongkul, T. Dechaprom, N. Phumivchuvate, L. & Losawatkul, S. (2006) 'Uncertainty appraisal coping and quality of life in breast cancer survivors' Cancer Nursing 29,(3), p.250-257.

Woogara, J (2005) 'Patients' rights to privacy and dignity in the NHS' Nursing Standard 19, (18), p. 33-37.

World Health Organisation (1995) 'International agency for research on cancer. european commission and survival of cancer patients in Europe: the Eurocare study in Lyon: IARC Scientific Publications. No 132.

Wright, E.P. Kiely, M.A. Lynch, P. Cull, A. & Selby, P.J. (2002). 'Social problems in oncology'. British Journal of Cancer 87, (10), p.1099–1104.

Yates, R. (2007) 'Behind the headlines' Cancer Research UK.

Yeo, W. Kwan, W.H. Teo, P.M. Nips, L. Wong, E. Hinly, L.Y. & Johnson, P. (2004) 'Psychosocial impact of breast cancer surgeries in Chinese patients and their spouses'. Journal of Psycho-Oncology 13, (2), p.132-139.

Yerrell, P. & Reed, A. (1997) 'The anachronism of policy for nursing in general practice: conceptualising a way forward'. Nursing Times Research 2, (4), p.245-257.

Yin, R.K. (1994) 'Case study research: design and methods'. (2<sup>nd</sup> ed.) Newbury Park: Sage Publications.

Yoshikawa, H. Weisner, T.S. Kalil, A. & Way, N. (2008) 'Mixing qualitative and quantitative research in developmental science; uses and methodological choices' Developmental Psychology 44, (2), p.344-354.

Zabora, J. BrintzenhofeSzok, K. Curbow, B. Hooker, & C. Piantadosi (2001) 'The prevalence of psychological distress by cancer site' Journal of Psycho-Oncology. 10, (1), p.19-28.

Zahl, P. Strand, B.H. Bjørn, H. & Mæhlen, J. (2004) 'Incidence of breast cancer in Norway and Sweden during the introduction of nationwide screening: prospective cohort study'. B.M.J. [online]. 328, (7445). Available from <http://www.bmj.com/cgi/content/full/328/7445/921> [Accessed 8th October 2007].



Ziebland, S. Chapple, A. Dunmelow, C. Evans, J. Prinjha, S. & Romzmovitis, L. (2004) 'How the internet affects patients' experience of cancer qualitative study' B.M.J.328, (7439), p. 564-582.

Zucker, D. M. (2001) 'Using case study methodology in Nursing Research'. The Qualitative Report. [online] 6, (2). Available from <http://www.nova.edu/ssss/QR/QR6-2/index.html>. [Accessed 8th December 2009].

## Appendix 1 Research Ethics Committee Consent

8<sup>th</sup> March 1999  
Ms Lorraine Kelly  
CNS Breast  
XXXXXX Hospital NHS Trust.

Dear Mrs Kelly

### **632 – Developing breast cancer follow-up services: The views of the users and GP's.**

I write to inform you that the above study has been considered by the Local Research Ethics Committee and has been agreed subject to the following proviso:

Add to consent form: that they have also read the information sheet and had an opportunity to ask questions/comment on the study.

Confirmation is required that the amendment has been incorporated before commencement of the study.

Yours sincerely

L.H Hipton

**XXXXXX HOSPITALS NHS TRUST**

**And**

**XXXXXXXXX UNIVERSITY**

**SCHOOL OF HEALTH, BIOLOGICAL**

**AND ENVIROMENTAL SCIENCE**

**CONSENT FORM**

**DEVELOPING BREAST CANCER FOLLOW-UP SERVOCES:**

**THE VIEWS OF USERS, GPS & TEAM.**

**I (Name of Subject).....**

**of (address).....**

**Confirm that I have read the nature and demands of the research and they have been explained to me allowing for questions. I understand and accept them. I also understand that I may withdraw from the research project at anytime if I find that I do not wish to continue for any reason without affecting my present or future care or relationship with the breast unit. I understand all information recorded will be kept confidential.**

**Signed .....**

**Date.....**

**Investigators Statement**

**I have explained the aims, purpose, nature and demands of the above research to the subject**

**Signature.....**

**Date.....**

Hospital Address

---

General Surgery & Urology/Oncology PMG

*The*  
*Breast Unit*

Dear

At present, Mr X , myself and other members of the Trust are trying to improve the breast services at XX Hospital. Together we are embarking on a research project in collaboration with the XX University as part of an M.Phil/PhD. This project should enable the team to implement some changes which could improve the care to the patients who attend the breast clinic for follow-up appointments.

Before we implement these changes we would greatly value your comments on the service and how we could make the follow-up clinics run more smoothly and understand the issues which are important to the professionals commissioning the service.

I have arranged to visit next week. I will bring a colleague with me, the other breast care nurse xxxxxxxxxxxxxx to scribe; therefore I should not miss important points. I look forward to our meeting next week. If there are any problems do not hesitate to contact me.

Yours sincerely

Clinical Nurse Specialist.

**XXXXXXX NHS TRUST**

**and**

**SCHOOL OF HEALTH AND SOCIAL SCIENCES**

**RESEARCH INFORMATION SHEET**

**DEVELOPING BREAST CANCER SERVICES: THE VIEWS OF USERS AND GPs**

**What is this research study about?**

We want to find out what users of breast cancer follow-up services, key staff and General Practitioners think about the sort of service that should be available. This information can then be used when we plan any further development.

**How will this information be collected?**

We will interview a group of women from the XXXX Breast Cancer Support Group who themselves have had breast cancer. We will also ask women coming to the follow-up clinic to complete a short questionnaire, and we will send a questionnaire to all GPs who send their patients to XXXX hospital for treatment of their breast cancer. We will also interview key members of the multidisciplinary team who care and treat patients diagnosed with breast cancer at xxxxxx Hospital.

**Do I have to be involved?**

Only if you choose to do so. We will ask for your consent before we collect any information from you, and you are perfectly free to refuse or change your mind at any time without it having any effect whatsoever on your medical care or your service contract or agreement with xxx hospital.

**What will you do with all of this information?**

Firstly we will make sure that any individuals who provide us with information cannot be identified - so your name and any other information by which you might be identified will not be stored with the information. We will make sure that all the information is stored safely, and no-one except the researchers will have access to it. Secondly we will analyse the information to determine what patients, GPs and key staff think about breast cancer follow-up service and how the service might be developed. We hope to be able to develop the service in the way which best meets the needs of both users and GPs.

**Will I be able to find out what happens?**

Yes, of course. We will provide a report on completion of the project which will be available on request in the breast clinic and will also be posted to GPs.

XXXXXXX NHS Trust

---

General Surgery & Urology/Oncology PMG

*The*  
*Breast Unit*

Dear

At present, Mr XXXX I and other members of the Trust are trying to improve the breast services at XXX Hospital. Together we are embarking on a research project in collaboration with the XXXX University as part of an M.Phil/PhD. This project should enable the team to implement some changes which could improve the care to the patients who attend the breast clinic for follow-up appointments.

Before we implement these changes we would greatly value your comments on the service and how we could make the follow-up clinics run more smoothly and understand the issues which are important to the professionals commissioning the service.

From the clinic list, you have an appointment in the next week or so. To enable us to seek the views and make changes to the service involving the people who use it, I wondered if you might be able to attend the clinic 10 minutes before your appointment time. Just 'check' into reception as always and you will be asked to complete a questionnaire. There will be some one to assist you. If you have any concerns do not hesitate to contact me.

Thank you in appreciation.

Clinical Nurse Specialist.

Appendix 6 questionnaire letter and questionnaire

XXXXXXXX NHS Trust

General Surgery &Urology /Oncology PMG.

*The Breast Unit*

01/06/2001

Dear Colleague

If you use the service of XXXX Breast Unit, please read on. If not please return in the pre stamped envelope.

The Breast Team at XXXX is trying to improve the breast services. Together we are embarking on a research project in collaboration with the XXXX University as part of my M.Phil. / PhD.

Before we consider any changes we need your input to help us decide how to change practice. We would greatly value your comments on the service and how we could make the follow – up clinics run smoothly and understand the issues which are important to the professionals who commission services.

I would be grateful if you could read the information, sign and complete the questionnaire and return by the Monday 18<sup>th</sup> June 2001. The signed form will be separated from the questionnaire. If you have any queries or concerns, do not hesitate to contact me directly on

020XXXXXX Office Hours

Aircall Message through Switchboard onXXXXXXXX.

Please Tick here ☐ if you would like information prior to publication

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Yours sincerely

Clinical Nurse Specialist.

XXXXXXX UNIVERSITY, XXXXXXXXXHOSPITALS TRUST.

**DEVELOPING BREAST CANCER FOLLOW-UP SERVICES: THE VIEWS OF GPS.**

*The XXXX*  
*Breast Unit*

1. What type of practice do you have?

Single handed

Group

2. Approximately how many patients are registered with your practice?

.....

3. What do you feel the benefits of attending follow-up breast cancer clinics are in general? Please rate each item from 1 (not important) to 5 (very important).

To feel confidence in progress	1	2	3	4	5
--------------------------------	---	---	---	---	---

To have adequate time to discuss concerns	1	2	3	4	5
---	---	---	---	---	---

Access to clinical team	1	2	3	4	5
-------------------------	---	---	---	---	---

Being able to see the same person	1	2	3	4	5
-----------------------------------	---	---	---	---	---

Any other reason

-----

4. What do you think are the benefits of hospital based follow-up?

.....

.....

.....



Appendix 6 questionnaire letter and questionnaire

5. What do you think are the disadvantages of hospital based follow-up?

.....

.....

6. How acceptable would you find the following types of follow-up clinic for your patients. Please rate each item from 1 (not at all acceptable) to 5 (completely acceptable)

Being seen by the doctor at the hospital  
(and being referred to the nurse if necessary)

Being seen by the breast care nurse at the hospital  
(and being referred to the consultant if necessary)

GPs to follow- up their own patients  
(and referring to hospital if necessary)

Being seen by the breast care nurse at a local GP practice  
(and being referred to hospital if necessary)

7. Do you feel GPs should play a greater role in follow-up care?

Yes

No

Uncertain

8. Would the choice of shared care between GPs and hospital be a workable option?

Yes

No

Uncertain

Appendix 6 questionnaire letter and questionnaire

9. Do you feel Patients should be offered a choice of follow-up?

Yes

No

Uncertain

10. Would you be willing to follow-up breast cancer patients at your practice?

Yes

No

Uncertain

11. Would you feel equipped to follow up breast cancer patients at your practice?

Yes

No

Uncertain

9. What would you require in order to be able to carry out breast cancer follow-up in your practice?

(Tick all that apply)

Additional training

Additional facilities

Additional Staff

Additional Funding

Appendix 6 questionnaire letter and questionnaire

None of the above

Other  
Please State

.....

10. Please add any comments you feel would help us to ascertain your views.

## Appendix 7 Focus Group Discussion Guidelines

- Dignity
- Waiting in clinic
- Waiting for treatments
- Continuity
- Health Education
- Reassurance
- Exam Techniques
- Feelings

## Appendix 8 Key Informant Interviews GP Guidelines

- Confidence
- Waiting in clinic
- Continuity
- Health Education
- Reassurance
- Shared Care
- Willingness to take on follow-up care
- Requirements to take on follow-up care

Appendix 9 Patient Questionnaire

XXXXXX UNIVERSITY AND XXXXXHOSPITAL

DEVELOPING BREAST CANCER FOLLOW-UP SERVICES: THE VIEWS OF USERS.

*The  
Breast Unit*

*Section 1 - To be completed by user*

1. What is your age?

18-25 •  
26-45  
46-65  
65-75  
Over 75
2. What is your occupation?  
(Or was, if retired)

.....
3. To what ethnic group do you belong:

Black Caribbean  
  
Indian  
  
Black African  
  
Other Asian  
Other Black  
  
Bangladeshi  
  
Chinese  
  
Pakistani  
  
Cypriot  
  
Irish  
  
White British  
  
Other  
Please state

## Appendix 9 Patient Questionnaire

4. Who examined you ,the last time, you came to clinic? Doctor ..... Specialist Nurse .....

5. What do you expect to happen at follow-up clinic?

.....

.....

.....

6. What do you think is the main purpose of attending the follow-up clinic?

.....

.....

.....

7. The way the service is currently organised, does it meet your needs? In relation to as many areas as possible could you tick the relevant boxes?

	Fully Met	Partially Met	Not Met
Maintaing dignity and privacy		•	•
Information		•	•
Being listened to		•	•
Adequate time		•	•
Seen as a person not a patient		•	•

## Appendix 9 Patient Questionnaire

8. The way the service is currently organised, how important are the points listed below? In relation to as many areas as possible, please tick the appropriate boxes.

	Very important	Important	Not Important
Maintaining dignity and privacy			
Information			
Being Listened to			
Adequate Time			
Seen as a Person not a Patient			

9. What do you feel the benefits of attending follow-up breast cancer clinics are? Please rate each item from 1 (not important) to 5 (very important).

To feel confident in progress	1	2	3	4	5
Information about the disease	1	2	3	4	5
Information about what you can do	1	2	3	4	5
Being able to see the same person	1	2	3	4	5
To feel reassured because the clinical team are content with your progress	1	2	3	4	5

Any other reasons

-----

-----



.....  
Appendix 9 Patient Questionnaire

10. How acceptable would you find the following types of follow-up clinic. Please rate each item from 1 (not at all acceptable) to 5 (completely acceptable)

Seeing my own GP  
(and being referred to hospital if necessary)

1      2      3      4      5

Being seen by the breast care nurse at a local GP practice  
(and being referred to hospital if necessary)

1      2      3      4      5

Being seen by the doctor at the hospital  
(and being referred to the nurse if necessary)

1      2      3      4      5

Being seen by the breast care nurse at the hospital  
(and being referred to the doctor if necessary)

1      2      3      4      5

**Please add any comments that you feel would help us to understand your views**

## Appendix 10 Clinical Variables

### *Section 2 - To be completed by breast care nurse*

8. According to the case notes, is the breast cancer recorded as:

Local disease ☐

Local disease with axillary involvement ☐

Recurrent local disease ☐

Metastatic disease ☐

9. According to the case notes what treatment has the patient undergone?  
(tick all that apply)

Local excision and axillary clearance ☐

Mastectomy and axillary clearance ☐

Radiotherapy ☐

Chemotherapy ☐

Other ☐

Please state ☐

.....

**Appendix 11 – Survivorship assessment.**

<b>Name</b> Mrs. M. Smith	<b>DOB</b> 10.08.1963	<b>Sex</b> Female	
<b>Cancer Diagnosis</b> – Breast	<b>Date of Diagnosis.</b> 23.06 2009		
<b>Date complete treatment</b> 21.05.2010	<b>Stage</b> Stage II	<b>Sites</b> Breast and 2 lymph glands	
	<b>History of Cancer Treatment</b>		
<b>Surgeon Name</b> Mr C Brown	<b>Phone</b> 0208 567 5678		
<b>Date of Operation</b> 1. 03.08.2009	<b>Procedure</b> 1.Modified radical mastectomy	<b>Pathology –</b> 1.Grade III Ductal ca. 5cms with LV invasion. 14/15 nodes + with extra nodal spread.	<b>ER</b> + --√ <b>PR</b> + --√ <b>HER2</b> √ + --
			<b>ER</b> + -- <b>PR</b> + -- <b>HER2</b> + --
	<b>Radiation Treatment</b>		
<b>Oncologist Name</b> Dr C White	<b>Phone</b>		
<b>Date range</b> 09/09-10/09	<b>Type</b>	<b>Field</b> Mastectomy wound and sub clav.	<b>Dose (in cGy);</b>
	<b>Chemotherapy / Drug Treatment</b>		
<b>Oncologist Name</b> Dr C Black	<b>Phone</b>		
Regime 1:	Cycles	Clinical Trial	
Regime 2:	Cycles	Clinical Trial	
Date Range		Date Range	
Other intervention			

Vascular Access		Yes /No		Insertion date	Removal Date		
Significant events during treatment		Weight gain > 10lbs Yes/No Psychosocial event requiring treatment		Weight Loss < 10lbs Major depression Yes/No	Cardiopulmonary event Anxiety Disorder Yes/No		
		<b>Follow-up Plan</b>					
Cancer Evaluation	Frequency	Symptoms to report					
Imaging		New lump <input type="checkbox"/>	New pain <input type="checkbox"/>				
Laboratory		Bleeding <input type="checkbox"/>	Cough persistent <input type="checkbox"/>	Bone pain <input type="checkbox"/>			
Physical exam		Change appetite <input type="checkbox"/>	Bowel habit change <input type="checkbox"/>	Head neck pain <input type="checkbox"/>			
			Fatigue <input type="checkbox"/>	Abdominal pain <input type="checkbox"/>			
Other		Nausea & vomiting. <input type="checkbox"/>	Weight loss > 10 lbs <input type="checkbox"/>				
<b>Other</b>		<b>Wellness</b>		<b>Cancer screening</b>	Date	Result	Next
Unable perform activities living <input type="checkbox"/> Anxiety <input type="checkbox"/> Depression <input type="checkbox"/> Psychosexual dysfunction <input type="checkbox"/> Inability to work <input type="checkbox"/>		Smoking cessation <input type="checkbox"/> Screening for osteoporosis <input type="checkbox"/> Nutrition & weight management <input type="checkbox"/> Physical activity <input type="checkbox"/> Safe sex <input type="checkbox"/> Sun exposure <input type="checkbox"/> Family History <input type="checkbox"/>		Mammogram Bone Density Bloods Examination Others	20.3.9 02.02.2010	Diagnosis NAD	03.03.2010 02.02.2011

Adapted from Haylock et al 2007.

## **ABBREVIATIONS, SYNONYMS AND NOMENCLATURES.**

A.S.C.O.	American Society of Clinical Oncology.
B.A.C.C.U.P	British Association of Cancer
B.A.S.O.	British Association of Surgical Oncology.
B.C.P.T.	Breast Cancer Prevention Trial.
B.M.J.	British Medical Journal.
C.D.C.	Centre for Disease Control - Cancer
C.H.I./A.C.	Commission for Health Improvement and The Audit Commission.
C.I.N.A.H.L.	Biomed, Cumulative Index of Nursing and Allied Health Literature
C.N.S.	Clinical Nurse Specialist.
C.S.C. – I.P.	Cancer Service Collaborative Improvement Partnership.
C.R.C.	Cancer Research Campaign
D.O.H.	Department of Health.
E.B.C.T.C.G.	Early Breast Cancer Trials Care Group.
G.I.V.I.O.	Interdisciplinary Group for Cancer Care Evaluation
G.P.	General Practitioner.
I.B.C.S.G.	International Breast Cancer Study Group.
I.B.I.S.	International Breast Intervention Study.
I.O.M.	Institute of Medicine.
L.F.T.	Liver Function Tests.
M.C.C.	Micro Calcification.
M.D.T.	Multidisciplinary Team.
N.C.C.S.	National Coalition for Cancer Survivorship.
N.C.I.	National Cancer Institute.
N.C.R.I.	National Cancer Research Institute.
N.H.S.B.S.P.	National Breast Screening Programme.
N.I.C.E.	National Institute for Clinical Excellence.

N.S.A.B.P.	National Surgical Adjuvant Bowel and Breast Project.
O.C.S.	Office of Cancer Survivorship
O.S.C.	Overview and Scrutiny Committee.
P.A.S.	Patient Administration System.
P.C.T.	Primary Care Trust.
P.P.I.	Patient and Public Involvement.
P.P.I.F.	Patient and Public Involvement Forums.
P.T.S.D.	Post Traumatic Stress Syndrome.
S.H.A.	Strategic Health Authority.
S.P.S.S.	Statistical Product and Service Solutions
U.I.C.C. T.N.M.	International Union Against Cancer. Tumour, nodes and metastases classification.
U.K.	United Kingdom.
W.L.E.	Wide Local Excision.
W.H.O.	World Health Organisation.